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**Male Involvement in Preventing Pediatric HIV Transmission:  
A Qualitative Analysis of Men's Roles in Sexual and Reproductive Health  
as told by Men and Women Living with HIV in Lilongwe, Malawi**

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2010

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An abstract of  
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## Abstract

# Male Involvement in Preventing Pediatric HIV Transmission: A Qualitative Analysis of Men's Roles in Sexual and Reproductive Health as told by Men and Women Living with HIV in Lilongwe, Malawi

By Megan E. Wichser

- Background:** Given that men often dominate decision-making about sexual and reproductive matters within sexual partnerships in resource-limited settings, positive male involvement and participation in the effort to prevent vertical and horizontal HIV transmission is critical. There is a strong evidence base that male involvement in family planning, voluntary HIV counseling and testing, and antenatal care improves the uptake of and increases adherence to PMTCT strategies in sub-Saharan Africa. Gender inequality is the most salient barrier to male involvement and has been studied very limitedly from a male perspective.
- Methods:** Qualitative data analysis was conducted on secondary data from 15 focus group discussions conducted on men and women of reproductive age living with HIV and attending ART clinics in Lilongwe, Malawi. Despite being situated in a capital city, these ART clinics serve both urban and rural Malawians. Participants were asked about their reproductive knowledge, attitudes, and practices.
- Results:** The five major themes that emerged from the data were: condoms; contraception; pregnancy and antenatal care; voluntary HIV counseling and testing; and ART. All five are components of comprehensive PMTCT programs. Gender norms and roles were found to strongly influence all themes. Within couples, men controlled condom use, family planning decision-making, and abortion decision-making, while also influencing HIV status disclosure.
- Discussion:** This study's findings revealed disagreement between men and women and among men themselves on men's roles in sexual and reproductive health. This dissonance challenges public health providers to structure interventions that function effectively within these multiple realities while also striving to improve them. Programs that incorporate these different beliefs, attitudes, and behaviors and also balance the knowledge that men often control decision-making within sexual partnerships with the rights of women to control their own reproductive health behaviors *and* work to break down harmful gender norms may effectively improve male involvement in sexual and reproductive health and subsequently reduce pediatric HIV infections.

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## **Chapter 1: Introduction**

### **1.1 Introduction and rationale**

In 2010, 390,000 children became infected with the Human Immunodeficiency virus (HIV), the cause of Acquired Immunodeficiency Syndrome (AIDS). Ninety percent of them acquired HIV through mother-to-child transmission (MTCT) during pregnancy, labor and delivery, or breastfeeding, and nearly all of them were born in sub-Saharan Africa (UNICEF, 2012). Global prevention of pediatric HIV is a sexual and reproductive health (SRH) priority and directly contributes to achieving 4 of 8 United Nations Millennium Development Goals - promoting gender equality and empowering women, reducing child mortality, improving maternal health, and combating HIV/AIDS, malaria, and other diseases (UN, 2012). The World Health Organization's (WHO's) 4-Component Strategy for the Prevention of MTCT (PMTCT) includes: (1) prevention of HIV in women, especially young women; (2) prevention of unintended pregnancies in HIV-infected women; (3) prevention of transmission from HIV-infected women to their infants; and (4) support for HIV-infected women, their infants, and their families (Pitter, n.d.). Women in sub-Saharan Africa make up over half of the HIV-positive demographic and are largely infected by their male sexual partners (John Ditekemena et al., 2012). Pregnant women experience a two-fold risk of contracting HIV compared to their non-pregnant counterparts, and because viral load is highest in newly-infected people, a newly-infected mother is likely to transmit the virus to her unborn child (Boyd, Brigham, Ewing, Newis, & Raistrick, 2009). Therefore, early detection, care,

and treatment of HIV-positive pregnant women and their partners is a WHO best practice approach for the “Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive” (WHO, 2010) (UNICEF & WHO, 2012).

SRH is an important issue in Malawi, which has the 9<sup>th</sup> highest HIV adult prevalence rate (11.0%) and the 14<sup>th</sup> highest total fertility rate (5.26 children born/woman) in the world (CIA, 2013a) (CIA, 2013b). The 2010 Malawi Demographic and Health Survey reports that 86% of women who gave birth during the two years preceding the survey received HIV counseling and testing during antenatal care visits. However, there is no data on their partners’ participation in HIV counseling and testing or their partners’ HIV statuses during the pregnancy. While coverage of HIV testing has increased between the 2004 and 2010 MDHS for both men and women, only 53% of men have been tested for HIV and received the results (in contrast with 73% of women) (USAID, 2011).

Decision-making around SRH in the context of HIV can be problematic for people living with HIV (PLHIV) and for public health and clinical care providers given the increased risk of horizontal (sexual) and vertical (mother-to-child) transmission of a chronic infectious disease (Cooper et al., 2009). This issue is exacerbated in pro-fertility, patriarchal settings where child bearing is universal and women’s ability to negotiate safe sex is limited (Basu & Mitra). In 2010, the global rate of MTCT of HIV was 26%. In high-income countries, it was 1%. This disparity

speaks to the structural and social barriers that low- and middle-income countries face in their effort to eliminate pediatric HIV (WHO, 2012).

Historically, the field of population studies has prioritized the reproductive knowledge, attitudes, and practices of women and neglected those of men in its study of the socioeconomic effects of population growth on societies. The landmark 1994 United Nations International Conference on Population and Development in Cairo identified the limitations of the women-centric model and served as a policy and programmatic wake up call for the inclusion of men. Its Program of Action catalyzed the paradigm shift from women-exclusive to male-inclusive SRH strategies promoting positive full participation and involvement of men in responsible parenting and SRH, including: family planning; antenatal, maternal, and child health; prevention of sexually transmitted infections, (e.g., HIV); and prevention of unwanted and high-risk pregnancies (Greene et al., 2006)

Research suggests that because men are key actors, “as individuals, as social gatekeepers, and as powerful family members who enforce cultural practices” (Greene et al., 2006), in SRH decision-making in sub-Saharan Africa, male involvement and support through the pathways of primary prevention and early public health strategies is a protective factor in the optimization of maternal and child health services (J. Ditekemena et al., 2012). Three approaches to involving men in SRH have evolved post-Cairo and include: emphasizing men as clients; emphasizing men as partners; and emphasizing men as agents of positive change,

respectively. The first strategy operated under the assumption that men's reproductive health needs were not being met. The second strategy operated under the assumption that men had central roles to play in supporting women's health. The third strategy is currently practiced and operates under the assumption that addressing inequity requires full participation and cooperation of men and promotes gender equity as a means of improving men's and women's health and as an end in itself (Greene et al., 2006).

The interaction between HIV and maternal and child health is particularly relevant to the study of male involvement in SRH. Studies indicate that countries with high HIV prevalence rates also have high HIV incidence rates in pregnant and post-partum women. This period of vulnerability highlights the need for partners of pregnant women to also be tested and treated for HIV (J. Ditekemena et al., 2012). Research supports that two SRH interventions at this crossroads are positively associated with male involvement: 1) voluntary HIV counseling and testing (VCT) and 2) prevention of mother-to-child transmission of HIV (PMTCT) (Katz et al., 2009) (J. Ditekemena et al., 2012). VCT and PMTCT are mutually reinforcing (Katz et al., 2009). Male partner involvement in antenatal voluntary HIV counseling and testing has been found to be a protective factor for increasing the acceptability and uptake of HIV prevention interventions such as PMTCT in resource-limited settings. PMTCT-related health processes that benefit from male involvement include: antiretroviral (ARV) prophylaxis uptake and adherence, family planning compliance, and optimal infant nutrition (Katz et al., 2009) (J. Ditekemena et al., 2012).

Similarly, “evidence indicates that male involvement can lead to contraceptive uptake through the pathway of increased spousal communication” (Hartmann, Gilles, Shattuck, Kerner, & Guest, 2012). Comparatively, male partner non-involvement in antenatal voluntary HIV counseling and testing has been found to be a risk factor for maternal-to-child transmission of HIV in exposed infants (J. Ditekemena et al., 2012).

The acceptability of male involvement in SRH is dependent on social, economic, political, and cultural factors, which need to be explored from both male and female perspectives (Greene et al., 2006). The literature also calls for a better understanding of the role of gender as a determinant of SRH decision-making among PLHIV in sub-Saharan Africa (Cooper et al., 2009).

## **1.2 Problem statement**

Positive full participation and involvement of male partners is essential to achieving the global elimination of pediatric HIV and an AIDS-free generation (WHO, 2010). Translating this knowledge into practice, however, requires a deeper understanding of barriers to positive male involvement in SRH in local contexts throughout sub-Saharan Africa. Failure to understand how societal attitudes and beliefs affect male involvement in family planning, VCT, and antenatal care could limit the effectiveness of an evidence-based public health intervention (PMTCT) that has the potential to prevent the spread of HIV (Greene et al., 2006).

### **1.3 Purpose statement**

The purpose of this study is to understand how to encourage positive full involvement and participation of male sexual partners in family planning, VCT, and antenatal care/PMTCT in order to reduce pediatric HIV incidence.

#### **Aims**

1. To understand how men and women living with HIV perceive men's role in family planning.
2. To understand how men and women perceive VCT.
3. To understand how men and women living with HIV perceive men's role in antenatal care.
4. To understand the interaction of gender norms with issues surrounding the acceptance of male involvement in sexual and reproductive health among people living with HIV.

### **1.4 Research questions**

1. What are the beliefs of men living with HIV about men's role in family planning?
2. What are the beliefs of women living with HIV about men's role in family planning?
3. What are men's perspectives about VCT?
4. What are women's perspectives about VCT?
5. What are the beliefs of men living with HIV about men's role in antenatal care?

6. What are the beliefs of women living with HIV about men's role in antenatal care?
7. How do gender norms affect attitudes about male involvement in SRH among PLWHIV?

### **1.5 Significance statement**

This research will provide a nuanced understanding of the range of pushes and pulls on male involvement and participation in sexual and reproductive health for PLWHIV in Lilongwe, Malawi. Garnering both male and female perspectives will be particularly useful for identifying discrepancies and variation in their knowledge and attitudes. The findings will be used to inform strategies for uptake and adherence to PMTCT at two anti-retroviral therapy (ART) clinics in Lilongwe.

## **Chapter 2: Review of the Literature**

### **2.1 The emergence of male involvement in sexual and reproductive health**

Historically, disciplines such as anthropology and demography have directed SRH research attention to the fertility behavior of women, prompting some critics to label men “the forgotten fifty per cent”. Varga suggests that this paradigm prevailed thanks to anthropology’s “theoretical preoccupation with feminism and gender definitions” and demography’s “(Western) normative views concerning women’s predominance in fertility and contraceptive use, and the assumption that – at least within marriage – men’s and women’s fertility interests are the same” (Varga, 2001). The last two decades have produced a growing body of literature that acknowledges shortcomings of traditional women-centered sexuality and reproduction research and calls for men’s positive full involvement and participation in sexual and reproductive health initiatives.

Despite recognition of this weakness in the literature, the majority of what is known about sexual and reproductive dynamics in sub-Saharan Africa derives from data on women. Researchers justified the conceptual omission of men by arguing that complexities and uncertainties of using men as research subjects or informants were problematic; they cited “the ill-defined span of men’s sexual lives, men’s assumed inability to report on their progeny, the analytic challenges posed by polygyny and extramarital partnerships, and the unlikely chance that they would be at home to be interviewed” to substantiate their claim (Greene et al., 2006).

Additionally, researchers approached SRH work with the assumption that parental

roles conform to a standard Western model, whereby women fill the primary childbearing and rearing roles, and men and women are thought to communicate openly and have the same outlook on reproductive matters. This model assumes that partners have a shared childbearing experience (i.e., “that either the relationship is monogamous and that all childbearing occurs within that union, or that the outside experience of the other spouse has no influence over childbearing in the current relationship”) (Greene et al., 2006). The reality of cultural variability of reproductive health environments renders this model inappropriate in societies where polygyny, marital instability, infidelity, imperfect communications, and women’s subordination are prevalent (i.e., practically everywhere). Therefore, social science perspectives on men and SRH have been disproportionately constructed through extrapolations from work with women (Varga, 2001). The neglect of men in sub-Saharan Africa-focused research and interventions has resulted in a reliance on stereotypes about male SRH knowledge, perception, and needs within the public health field (Varga, 2001).

Only in the last 15 years has data coverage in the field of SRH expanded from its traditional study population of married women of reproductive age to include men aged 15-54 in nationally representative surveys in about 40 developing countries. These surveys were motivated by the global challenges resulting from the HIV/AIDS epidemic, which increased awareness that prevailing women-centric reproductive health programs were having a limited impact on reaching overall reproductive health and development goals (Greene et al., 2006).

## 2.2 Gender roles and norms

Gender roles and norms influence and determine the extent of male involvement in sexual and reproductive health, particularly in sub-Saharan Africa (Onyango, Owoko, & Oguttu, 2010). Within the field of HIV prevention, interest is mounting about the role that gender plays in HIV and violence risk and consequently on positively involving men in the response (J. Pulerwitz, Michaelis, Verma, & Weiss, 2010). Research indicates that behavioral norms frequently promote unequal gender roles and responsibilities, which support behaviors that put both men and their sexual partners at risk of negative health outcomes, (e.g. HIV). Such norms for men include having an early sexual debut, having multiple sexual partners, and lying about being knowledgeable about sexual matters. Further, gender norms that situate men in positions of sexual dominance also limit women's control over their own sexual and reproductive health (J. Pulerwitz et al., 2010).

Pulerwitz et al. compiled a portfolio of findings from more than 10 Horizons program studies in Asia, Africa, and Latin America, conducted from 1997 through 2007, that have explored the relationship between gender and men's behaviors, developed useful measurement tools for gender norms, and evaluated the impact of gender-focused program strategies (J. Pulerwitz et al., 2010). A longitudinal evaluation of an education and media campaign targeting young men aged 14 to 25 in Brazil (2002-2004) found that positive changes in gender attitudes increased condom use at last sex and reduced STI symptoms (Julie Pulerwitz, Barker, Segundo,

& Nascimento, 2006). Another longitudinal evaluation of a pilot education campaign targeting young men aged 18 to 29 in India (2004-2005) found that positive changes in gender attitudes also improved partner communication and sexual health problems and reduced STI symptoms and partner violence (Verma et al., 2006). These studies demonstrate the feasibility and effectiveness of working with young men to challenge negative gender norms as they begin to navigate sexual and romantic relationships for the first time. Horizons researchers developed and validated the Gender Equitable Men (GEM) Scale to quantitatively measure change in attitudes about gender norms. They found a relationship between more support for gender equitable norms (i.e., higher GEM Scale scores) and less-reported partner violence, more contraceptive use, and a higher education level. Overall, Horizons research findings support that gender norms often play a powerful role in perpetuating HIV risk behaviors and that interventions promoting equitable gender norms are relevant HIV prevention strategies. However, there is also a need to evaluate strategies that target both men and women (J. Pulerwitz et al., 2010).

### **2.3 Male involvement in the avoidance of unwanted pregnancy**

There is a scarcity of published evaluations of interventions that seek to promote male involvement in family planning in the literature, however existing data indicates that male involvement can lead to contraceptive uptake through the pathway of increased spousal communication (Hartmann et al., 2012). A randomized controlled trial evaluating the impact of the Malawi Male Motivator project, a theoretically based male-targeted family planning intervention that used

male peer educators to increase use of family planning among young Malawian couples, found that increased ease and frequency of communication between partners was a significant predictor of contraceptive uptake (Shattuck et al., 2011). The intervention built upon a growing body of research demonstrating that men usually receive reproductive health information from peers.

Structurally, the intervention was based on the information-motivation-behavioral (IMB) skills model, which postulates that “motivation to adopt a preventive practice and the provision of relevant information lead to the activation of behavior skills and the consequent adoption and maintenance of behavior change” and has been used within the reproductive health field to engage with HIV prevention, condom use, and adolescent contraceptive use programming (Shattuck et al., 2011). For the Malawi Male Motivator project, which was the first application of this model for the promotion of male involvement in contraceptive use, the 3 fundamental determinants of couples’ uptake of modern contraceptive use were: (1) information on modern family planning methods and locally available resources; (2) motivation to act on knowledge and adopt family planning practices (dependent on attitudes about contraception, perceived social norms, and personal expectations about family size); and (3) behavior skills relevant to family planning (e.g., interpersonal communication, condom proficiency). The evaluation findings indicate that the content and processes (training in communication skills) of the Malawi Male Motivator project were effective mechanisms for enabling men to facilitate contraceptive use for their partners. Potential covert partner use of

contraceptives, which has been well documented in the literature, during the baseline survey of male participants could have limited the quality of this study. Additionally, the IMB model did not completely elucidate the success of this intervention; there is a need to continue to test theoretical models to gain a better understanding of complex health behaviors and relationship dynamics (Shattuck et al., 2011). Hartmann et al. suggest that Rogers' six-stage model of communication effects on family planning, which considers many of these factors, may be a more appropriate fit for engaging with spousal communication regarding family planning from a male involvement perspective (Hartmann et al., 2012).

There is a wide and multifaceted scope of determinants and influences on spousal communication (Hartmann et al., 2012). In sub-Saharan Africa, gender roles and norms interact with spousal communication and resultant family planning decision-making in significant ways. Despite contraceptive methods and services' female target clientele, men often control decision making about family size and their partner's use of contraception, making male opposition to family planning a relevant challenge (Hartmann et al., 2012). A qualitative study conducted in Kenya found that men were opposed to their partners using contraceptives because they feared the practice would fuel marital infidelity (Hartmann et al., 2012). Male attitudes toward family planning also indirectly affect contraceptive use decisions. In the absence of explicit communication, women often inaccurately judge their partners' feelings toward family planning as unsupportive, causing them to use contraception in secret or not at all (Hartmann et al., 2012). While the association

between spousal communication and contraceptive use is well documented in the literature, there is a gap in knowledge about the dynamics of this communication (e.g., “the content, pattern of initiation, and pattern of decision making around contraceptive use decisions, and how men and women perceive this process in the context of their relationship”) (Hartmann et al., 2012). Current research on spousal communication and family planning use has yielded inconsistent findings. A study in Pakistan found that male-initiated conversations about family planning were more likely to lead to contraceptive use than those initiated by women (Saleem & Isa, 2004). However, another study found that contraceptive use was associated with joint decision making more so than individual decision-making, and a third study found the same association ambiguous (Hartmann et al., 2012). Qualitative research is valuable for understanding complex interpersonal interactions, and has only been applied limitedly to explore the role of communication initiation and decision-making within male involvement interventions (Hartmann et al., 2012).

#### **2.4 Male involvement in antenatal care/PMTCT and VCT**

Ditekemena et al. conducted a systematic review of the literature and found that a precise and universally accepted definition of male involvement in PMTCT is nonexistent. Its meaning varies by author, with some authors defining “male involvement” as male partners’ participation in HIV testing only during antenatal care and others as participating in HIV couples’ counseling and testing (J. Ditekemena et al., 2012). The composite term “Male Involvement and Participation” (MIP) in the PMTCT will be used for the purposes of this literature review.

Adherence to PMTCT programs is a challenge throughout all sequential stages of the WHO-recommended approach, which includes: antenatal care; comprehensive counseling and testing, post-test counseling and referral of HIV-positive mothers and their families to ART programs; program enrollment; the offer, acceptance, and intake of single-dose of nevirapine for seropositive mothers and their newborns; safe feeding instruction and practice for the infant; and follow-up visits, respectively. Dropout rates during the different steps of the intervention exhibit a cascade-like pattern, with fewer participants remaining at each successive step. Research findings indicate that program refusal or later-on dropout may be partially explained by the role that social support plays in facilitating women to make the required serial decisions and adhere to the course of the intervention. The literature suggests that male partners often influence pregnant women's behavior, particularly in patriarchal, low-resource settings such as sub-Saharan Africa. Increasing MIP as a strategy to enhance implementation of PMTCT has been identified in the literature as especially relevant for HIV priority countries considering their high rates of HIV among women of reproductive age and maternal seroconversion during pregnancy (Theuring et al., 2009).

Peltzer et al. suggest a need in the literature for group-randomized trials at the couple-level evaluating the impact of combination evidence-based interventions, such as a couple's risk reduction intervention combined with an evidence-based medication adherence intervention to improve ARV and PMTCT adherence in

antenatal clinics, that are mediated through the pathway of MIP (Peltzer, Jones, Weiss, & Shikwane, 2011).

Antenatal VCT functions as the point of entry for the targeted prevention of MTCT of HIV (Katz et al., 2009). Farquhar et al. observed that MIP in antenatal VCT was associated with increased uptake of interventions to prevent vertical and horizontal transmission of HIV (Farquhar et al., 2004). Couple VCT was found to have a greater impact on preventing transmission of HIV than male partners accompanying female partners for individual VCT (Farquhar et al., 2004). However, the literature indicates that men rarely accompany their female partners to antenatal clinics, and even more rarely participate in couple VCT (Katz et al., 2009). There is limited research about men's perspectives on MIP in antenatal VCT in the developing world. One study conducted in Kenya used a pre-test/post-test control group design targeting couples who presented together at an antenatal clinic in Nairobi to assess male attitudes toward VCT (Katz et al., 2009). It found that men who participated in couple VCT were younger, had fewer children, and were less knowledgeable about PMTCT than men who participated in individual VCT (Katz et al., 2009). Most (94%) men expressed positive attitudes about receiving VCT in the antenatal context, which suggests that antenatal clinics may be an acceptable location for VCT for men. These findings are limited in that selection bias may have been at play given that men presenting at the clinic may differ from men not presenting at the clinic in meaningful ways. For example, acceptability, motivations, and barriers reported by men accompanying their female partners to antenatal

clinics may not be representative of all men with pregnant partners (Katz et al., 2009).

Morfaw et al. conducted a systematic literature review to identify barriers and facilitators to MIP in PMTCT and found that barriers to MIP were largely at the societal, health system, and individual level (Morfaw et al., 2013). They identified the societal perception of antenatal care and PMTCT being a woman's activity as the most prominent barrier (found in 9 of 24 studies). Other societal level barriers included: societal ridicule of men accompanying their wives to antenatal services; conflict between PMTCT recommendations and cultural norms such as breastfeeding; and cultural patterns of communication. Barriers identified at the health system level included: long waiting times at the clinic; antenatal services being not male-friendly; and distrust in the confidentiality of the health system. Reluctance to learn one's status and lack of time for antenatal care/PMTCT were identified as prominent male individual factors impeding MIP. Knowledge barriers, such as the misconception that your partner's HIV status is a proxy of your own status, were also observed. They found that facilitators to MIP were largely at the health system and individual level. The most prominent health system level facilitators were invitation letters from health services inviting men to PMTCT and offering routine VCT. Provision of counseling services during non-working hours and offering of VCT at alternative sites (i.e., not at antenatal clinics) were also found to be health system level facilitators. Having been previously tested for HIV, having time provided to consider PMTCT recommendations, and being educated on the

benefits of PMTCT were identified as male individual factors facilitating MIP. See Appendix 1 for summary tables of barriers and facilitators of male PMTCT involvement and participation (Morfaw et al., 2013).

## **2.5 Summary**

Global health interest in MIP in SRH has been emerging in the literature over the past couple of decades. This new focus on men was prompted by a paradigm shift from traditionally women-focused SRH research and programming, in large part due to the global challenges of the HIV epidemic. MIP in family planning, VCT, and antenatal care has been shown to improve uptake of and increase adherence to contraception and PMTCT strategies in sub-Saharan Africa. The literature, however, is limited by its reliance on women's perspectives of men's involvement and participation. Qualitative research provides a valuable opportunity to understand the barriers and facilitators of male involvement and participation in PMTCT in greater depth.

## **Chapter 3: Methods**

### **3.1 Introduction**

This study was performed using secondary data collected in 2012 for a mixed-methods reproductive health assessment of people living with HIV in Lilongwe, Malawi<sup>1</sup>. The aim of the project was to assess the current reproductive health knowledge, attitudes, and practices of individuals with HIV attending ART clinics. Dr. Lisa Haddad from Emory University School of Medicine was the principal investigator (PI) and collaborated with the University of North Carolina Project-Malawi (Lilongwe, Malawi), the Lighthouse Trust (Lilongwe, Malawi), and the University of North Carolina at Chapel Hill (Chapel Hill, USA) on this project. The data was collected and evaluated in three phases and consisted of focus group discussions (FGD), in-depth interviews (IDI), and structured questionnaires, respectively. Only the FGD data were used for analysis purposes for this particular study.

### **3.2 Population and sample**

Focus groups were conducted at the two Lighthouse Trust ART clinics (the Lighthouse Clinic at Kamuzu Central Hospital and the Martin Preuss Centre at Bwaila Hospital) in Lilongwe, Malawi. Despite being a capital city, Lilongwe's

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<sup>1</sup> Title of study: "Exploring the Impact of HIV and ART on Knowledge, Attitudes and Practices in Reproductive Health in Lilongwe, Malawi"; Funding provided by: The Society of Family Planning (SFP); P.I.: Lisa B. Haddad; IRB # 00051780.

residents are both urban and rural. The Lighthouse Trust is a Centre for Excellence for Integrated HIV Management that provides VCT, clinical care (including provision of ARVs), and community home-based care. Between its two clinics, Lighthouse Trust has over 15,000 clients on ART and 3,200 clients living with HIV who are pre-ART. The two target populations were male clients living with HIV on ART and female clients living with HIV on ART. Other selection criteria included: being a registered client at either of the participating Lighthouse Trust clinics; having been on ART for the past six months; being between 18 and 45 years of age; and having been sexually active within the past six months. Respondents were purposively sampled from the waiting rooms of the two ART clinics and from nurse referrals following their visits. Researchers identified and recruited participants whom they perceived able to provide the most information to meet the research objectives. Each focus group consisted of six to eight respondents and lasted one to two hours. A total of 19 FGDs were conducted (nine at the Lighthouse Clinic and ten at the Martin Preuss Centre). Overall, 56 men and 60 women participated in the discussions. The researchers had originally intended to conduct a minimum of four and a maximum of eight focus groups from each target population; the number of focus groups was determined based on data saturation. Ultimately, eight men's focus group discussions (three from the Lighthouse Clinic and five from the Martin Preuss Centre) and seven women's focus group discussions (three from the Lighthouse Clinic and four from the Martin Preuss Centre) were used for secondary analysis.

### 3.3 Instruments

FGD guides were based on the following domains:

- Fertility intentions: Perception of ideal family size, including social, familial, and partner pressures regarding fertility; the influence of HIV and ART on these intentions; concordance among couples on fertility intentions; how relationship status influences fertility intentions; and reproductive health issues which may influence fertility intentions
- Family Planning: Knowledge regarding family planning in general and specific understanding of methods; misconceptions and beliefs regarding specific family planning methods; current or previous use of family planning methods; desire/intention to use family planning methods; social, familial, and partner influence on family planning method use; and the influence of HIV and ART on use/non-use
- Sexual health behaviors: The influence of HIV/ART on use/non-use of dual protection; perception of sexually-transmitted infection (STI) risk; and perception of risk of HIV transmission to partners or children

FGD guides were developed in English, translated to the local language (Chichewa), pilot-tested, and adjusted by the research team prior to data collection. The discussion guides included an introduction, introductory questions, transition questions, key questions, probes, and closing questions. Copies of both the English

and Chichewa discussion guides may be found in Appendix 2. Facilitators (four), note-takers, and translators from the organization Research for Equity and Community Health (REACH) Trust were familiarized with the study and trained in qualitative research methods for three days prior to conducting the FGDs. Topics covered included: the study background, objectives, and research methods, including general moderating techniques and procedures such as probing; and ethical considerations of the study, including obtaining consent from clients, questioning techniques, and maintaining neutrality, privacy, and confidentiality. A brief intake questionnaire was prepared and administered at the beginning of each FGD to collect information on participant demographics and fertility desires. Discussions were held in enclosed rooms free from external distractions. Refreshments were provided at each discussion, and participants were reimbursed for their transportation fees.

### **3.4 Data preparation and analysis**

All FGDs were tape-recorded, transcribed, translated, and de-identified verbatim from Chichewa to English. Qualitative data analysis was conducted using MaxQDA10 software. During an initial reading of the transcripts, the data was annotated with memos to record reflexive notes about the researcher's first impressions of the content of the discussions as well as explicit issues raised by the participants. Memos were also used to note recurring concepts and hypothesized relationships in the data during subsequent readings of the transcripts, which ultimately aided in the development of a preliminary inductive codebook. The

codebook underwent several revisions during the process of developing research questions and after fitting it to four dissimilar transcripts (one male and one female from the Lighthouse Clinic and one male and one female from the Martin Preuss Centre). The final refined codebook was applied to all 15 transcripts; see Appendix 3 for the codes and their definitions.

Emergent themes were analyzed within all of the male transcripts, followed by all of the female transcripts. They were then cross-analyzed. Textual segments were searched and reviewed using individual codes and intersections of codes.

### **3.5 Limitations**

The main limitation of this study was its use of secondary data that was not collected with the same research aims or for the same purpose. While the data aimed to assess the reproductive health knowledge, attitudes, and practices of HIV-infected men and women attending a public ART clinic, this study focused specifically on positive MIP in family planning, VCT, and antenatal care to facilitate the prevention MTCT of HIV. The FGD guide did not include questions to probe for discussion on these specific topics, so the relationship between male involvement and participation and prevention of MTCT had to be studied from discussions of other themes.

Additionally, although 19 focus group discussions were conducted, only 15 could be used for analysis purposes. Three of the focus group discussions were

taped over by the original research team, and there were two instances of duplicated transcripts. The tape-recorder battery ran out during one focus group, thus cutting off part of the discussion. The loss of four transcripts and part of one other discussion may have compromised the data quality. Additionally, because the transcripts were translated from Chichewa to English, it is likely that some meaning could have been lost in the translation.

The intake questionnaire with demographic and fertility preference information was only included in six of the 15 transcripts. In all but one transcript, the participants were unidentifiable. It was very difficult to decipher which participants were talking and when (e.g., if someone was dominating the conversation, not talking at all, etc.). This made it nearly impossible to discuss pervasiveness of themes in terms of what proportion of participants shared a particular viewpoint. The language of, “one, a couple, a few, most, or all” was used to approximate pervasiveness; it should be noted that these terms cannot be further qualified since participants were not identified in the transcriptions.

### **3.6 Ethical considerations**

The study was submitted to the Emory University Institutional Review Board (IRB), the University of North Carolina Institutional Review Board, and the National Health Sciences Research Committee within the Malawi Ministry of Health for approval prior to initiating the study. Copies of approval forms may be found in Appendix 4.

REACH Trust's researchers were experienced and skilled in conducting research on sensitive topics. They were prepared to navigate challenging emotional issues, such as respondents emotionally breaking down during the discussions.

All potential study subjects gave informed consent before participating in any phase of the study, and anyone with questionable capability to give consent was not enrolled. Participants could opt-out of participating in the study at any time. The inclusion criteria excluded minors from participating. No photos of participants were taken. FGDs were conducted in private rooms with strict adherence to confidentiality guidelines on the part of the researchers. All data was de-identified and only accessible to the research team. HIPAA compliance was adhered to.

The researcher was certified by the Collaborative Institutional Training Initiative (CITI) on Human Subjects Research. Before initiating secondary data analysis, it was determined that IRB approval or exemption for the intended analysis was not required because a non-Human Subjects Research status was confirmed by Emory's IRB staff via email due to the nature of the secondary, de-identified data. Additionally, this project did not meet the Federal definition of "research" due to the fact that its findings are specific to this population and are not generalizable outside of Lilongwe, Malawi. Instead, it is classified as public health practice because its findings will inform Lighthouse Trust's ART programs.

## Chapter 4: Results

Preliminary data analysis revealed five major themes from discussions on men's roles in SRH. All other codes targeted these five themes, which were: condoms; contraception; pregnancy and antenatal care; VCT; and ART and ARVs. Gender norms were found to impact the themes significantly. This chapter will describe each component of comprehensive PMTCT programs (i.e., the five themes) and the effect that male involvement has on each.

### 4.1 Condoms

#### *Expectations of Condom Use*

All male respondents conveyed the belief that people living with HIV are supposed to use condoms regularly, or during every sex act. Most men thought that condoms are good for people living with HIV because they put the user in the driver's seat to control viral load, sexually transmitted infections, and pregnancy.

When asked, nearly all male respondents expressed the opinion that condoms are the best contraceptive method for people living with HIV. One respondent disagreed and asserted that abstinence is the best method. All men viewed regular condom use as a consequence of the HIV epidemic and talked about it as a chronic, life-long personal health practice in response to an HIV diagnosis.

*You are supposed to take drugs the rest of your life, as with condoms - you are supposed to use them the rest of your life.*

-Male MPC FGD 2

Men cited ART clinic patient educators, who promoted condoms as the gold standard contraceptive method for people living with HIV, as the source of this idea. The radio was also credited with perpetuating this message.

Most male respondents mentioned the belief that couples with at least one HIV-positive partner are not supposed to get pregnant. Most men indicated that HIV-positive pregnancies are problematic due to the toll they take on the mother's immune system as well as the risk they carry for the baby. However, one male participant thought that an exception to the rule should be made for HIV-positive couples with fewer children, but that they should start using condoms after achieving their desired number of children. Most male respondents said that once pregnant, couples should use condoms to protect against transmitting HIV to the baby.

*Again, when the woman is pregnant, you are not supposed to have unprotected sex; you need to use condoms to avoid transmitting your HIV to the baby.*

-Male MPC FGD 4

Most female respondents talked about using condoms regularly during an HIV-positive pregnancy as an absolute, and several described their own experiences doing so.

Female respondents were more vocal than male respondents about how society's expectations of condom use for all people seemed to vary by relationship type. Several women discussed the belief that unmarried couples are expected to

engage in protected sex, while married couples living without HIV are expected to engage in unprotected sex. Most female participants thought that men expected couples to adhere to society's standards of condom use (e.g., unprotected sex in marriages) rather than those of the medical community regardless of HIV status; this tension was conveyed throughout all of the discussions with women and was perceived by them as problematic.

### ***The Meaning of "Protection"***

In all focus group discussions, the concept of "protection" seemed larger than just a physically protected sex act. Most groups identified the HIV epidemic as the driver of a cultural shift that amplified their perception of danger in their environments. Condoms were viewed by all as a tool to shield oneself from said danger, thus giving people autonomy in a situation that felt constricting and beyond their control. This perspective inspired one man's opinion that condoms are a human right. Most men and women indicated that the function of condoms is to protect not only oneself, but also one's partner and one's existing and future children. Many viewed protection in this vein as an act of love. While most men and women talked about condom use in terms of family security, several respondents also alluded to its role in establishing communal and national security. Most men regarded unprotected intercourse as inappropriate and dangerous outside of marriage because sex without a condom seems to symbolize a deeper trust and commitment to their partner. One male respondent asserted that women do not feel

safe when their partners use condoms and that women want to have unprotected sex so their partners can demonstrate their commitment to them.

*Like in my case, I am not married but am preparing to marry, and when we are having sex, each time I use condoms she does not feel safe. She would love to have unprotected sex in order for her to believe that I am indeed her man, and sometimes she plays tricks to prevent me from using the condom, and I finally succumb to them.*

-Male MPC FGD 5

Several male respondents viewed unprotected sex as self-indulgence for people living with HIV. Despite awareness of its taboo status, these men acknowledged the reality that people living with HIV engage in unprotected sex. They conveyed that even couples actively trying to adhere to regular condom use either “slip up” or “treat themselves” to sex without a condom from time to time. Their female counterparts designated unprotected sex “entertainment.” This term was applied to contrast the monotony of protected sex for people living with HIV.

One female respondent described protected sex as a means of “satisfying nature,” thus, classifying sex with condoms as meeting a basic physiological human need. Alternatively, she viewed sex without condoms as meeting a more complex social human need – sexual intimacy. Her distinction between protected and unprotected sex gets at the incomplete fulfillment (e.g., only of the physical) that protected sex allows.

Both a male and a female respondent labeled unprotected sex as unplanned sex. However, one woman asserted that some men do not consider protected sex

“sex.” Most female respondents associated sex practices with character; they considered people living with HIV who engage in unprotected sex irresponsible and present-oriented and those who engage in protected sex responsible and future-oriented. One female respondent asserted that men demonstrate their commitment to their partners by following through with their promise to use condoms during every sex act. Most women discussed the ability of condoms to keep their users’ bodies strong (e.g., maintain viral load); they considered protected sex a health wellness practice.

The concept of protection thus carried a multiplicity of meanings, and not all were complementary.

### ***Promiscuity and Stigma***

Although condoms were regarded as a tool for self-preservation in all focus group discussions, all men took issue with married women carrying condoms in their handbags. Several men used the terms “bitch,” “prostitute,” and “promiscuous” to describe married women who carry condoms in their handbags. Nearly all men associated women carrying condoms in their handbags with prostitution when the condoms were carried anywhere other than from the hospital or grocery store to the home. They expressed the idea that society allows unmarried women to carry condoms in their handbags to destinations other than their homes, but does not allow married women to do so unless they are traveling with their husbands to an overnight destination. Most men explained these beliefs with the perception that

unmarried (and not married) women are at risk of contracting HIV, as they considered these women's sexual encounters unpredictable.

Most men thought that married women who carry condoms in their handbags engage in extramarital sex. Several male respondents asserted that if they found condoms in their wives' handbags, their wives could expect divorce because of this assumption. One male respondent used an analogy to discuss society's attitudes about the appropriate location of condoms within a marriage:

*F: Alright, so you feel it is acceptable for a woman who is not married to carry a condom and suggest that her partner use it when they meet? That's okay with you?*

*In Unison: Yes, there is no problem.*

*F: But a lady who is married?*

*R: For a married woman, if condoms are in the house, they are like plates. After walking around, she will come to use the plates right at home so it's the same way with condoms.*

*F: If she carried the plates with her where she is going, you would ask her, 'Are you going to cook **nsima**<sup>2</sup> right there?'*

*R: Yes you would ask, 'Are you going to cook nsima there?' (laughter).*

-Male MPC FGD 1

One man expressed disagreement, saying that everyone should carry condoms out of respect for their own lives:

*Everyone is supposed to carry a condom. There is no reason to judge someone just because she is carrying a condom. We have the perception that if we see a lady carrying a condom in her bag, we say, 'This is a prostitute,' yet she is only doing that to protect her life ... So it is a universal right to carry condoms in order to protect oneself, and a woman is free to carry condoms and suggest that her partner use them.*

-Male MPC FGD 3

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<sup>2</sup> "**nsima**" is a cornmeal product and staple food in Malawi.

Another male respondent shared his opinion that men (not women) developed sexual desires and should therefore be responsible for producing condoms.

A few women discussed covert use of the female condom as a means to avoid social ridicule from carrying male condoms. A few others shared complementary beliefs to their male peers about the appropriateness of married women carrying condoms in their handbags:

*I never knew a woman can carry condoms but I knew it from where I work. There is a daughter of my boss and she said, ‘\_(name removed)\_, look at my handbag, there are condoms inside. I have a boyfriend at such and such a place, and I meet him because my husband has a secret lover. I saw condoms in his bag, and I have decided to carrying condoms as well’. I was very surprised that a woman can carry condoms with her. How can you open up to a man who is your lover and tell him, ‘Here are the condoms,’ when maybe it’s a man you just met unexpectedly? When you do that it’s like you have exposed yourself as the most experienced whore ever ...*

-Female MPC FGD 4

However, most women did not differentiate said appropriateness by marital status, rather promoting the practice of all women carrying condoms:

*You can tell him, ‘Life nowadays is dangerous. HIV exists, and that’s why I carry condoms. If you want me, here is the condom. Use it. If you don’t want to use it, let’s call it quits.’*

-Female MPC FGD 1

Several female respondents talked about the issue of disclosing their HIV status to a new partner following the death of a former spouse. They identified the expectations that married couples engage in unprotected sex and that each marriage produce children as deterrents for disclosing their HIV status, fearing that their new partner would leave them. Rather than navigate these issues, the women discussing

them chose to avoid the situation altogether by remaining unhappily single in widowhood.

### ***Condom Acceptability, Negotiation, and Partner Refusal***

All men were more knowledgeable about male condoms than female condoms, which most had never seen or used. The few who had used them complained of their noisiness and interference with intimacy. Most male respondents also criticized male condoms. Several men thought of condoms (especially the lubricated variety) as “adding diseases,” such as chafing, sores on men’s genitals, and stomachaches in women. A few male participants thought that condoms are not 100 percent trustworthy due to their tendency to break during intercourse. Most men perceived protected sex to be less enjoyable than unprotected sex. Several men thought of condoms as negatively impacting their sexual experience:

*There is a difference in performance when you use a condom and when you do not use one. When you do not use a condom, you both feel each other during sex. But if you use a condom, you just feel yourself - your partner does not feel anything, and that’s the reason why she insists that you have unprotected sex.*

-Male MPC FGD 5

One male respondent asserted that protected sex is not as “sweet” as unprotected sex. Several male respondents described married couples experiencing condom fatigue and subsequently negotiating breaks from regular condom use every few months. One man worried that by having condoms in his household, his adolescent children would see them and be inclined to experiment with them; he was fearful that this would “fuel bad practices.” Several male respondents discussed

the issue of men refusing to use condoms with their partners. One man explained this phenomenon by asserting that men are negligent and selfish. Another male respondent blamed men for the negative consequences of unprotected sex:

*Maybe it's something that we already mentioned - that it is us men who are wrong. Like he mentioned, we need to be using condoms. But in most cases, we feel we have not enjoyed you - have not had sex with you. That's why we decide to leave condoms aside, and women are never strong enough to deny us that. The end result is that they become pregnant when they are not ready. When they go to the hospital, the doctor tells them, 'You seem pregnant, were you not using condoms?' And they tell him, 'My husband did not want to use them.' You see?*

-Male LH FGD 1

However, one man mentioned that women “play tricks” on men to avoid using condoms. Several men noted, though, that women lacked power to negotiate condom use during the act of sex, as men are physically stronger than women.

All women believed that men were opposed to using condoms, while they themselves expressed no opposition to the practice.

*Condoms are important for us, but our husbands refuse to use them most of the times.*

-Female LH FGD 2

*Most of the time, it is men who are not comfortable with using condoms. They do refuse them, but with us women there is no problem.*

-Female LH FGD 1

Several female respondents indicated that men had more control over condom use. However, several others expressed the idea that women did have agency in negotiating condom use and could refuse their partners sex if men refused to use condoms.

*F: Why is it that women have no problem using condoms, but men do not allow them?*

*R: They say they don't want to eat a sweet in its paper - they want it plain. But as a woman, you still talk to him about using a condom because you get worried, thinking about viral load. After persuading him to put on a condom, you will find he has allowed it, but most men don't allow using condoms during sexual intercourse.*

-Female LH FGD 1

Yet, women viewed this as problematic within marriage because they said that men often threatened to leave their spouses for women willing to have unprotected sex (as in the case of one of the participants). In all focus group discussions with women, respondents noted men's argument that, "One does not eat a sweet while it's in its paper." One woman mentioned hearing men say that HIV-positive concordant couples need not use condoms (a common explanation men gave for refusing to use them) and indicated that it was a serious issue. Several women discussed using a backup contraceptive method in order to avoid pregnancy if their partner refused to use condoms; some of them used dual protection covertly. Overall, partner refusal to use condoms was talked about more by woman than by men.

## **4.2 Contraception**

### ***Decision-Making around Contraceptive Use***

Most male respondents communicated that decision-making around childbearing and consequently contraceptive use is influenced by a couple's financial status and HIV status. Emphasis was placed on men's financial status and on women's HIV status; these male respondents conveyed that men spend more

time thinking about their financial situation, while women spend more time thinking about their health situation when making decisions about childbearing. These men viewed being poor as a universal limitation on childbearing, whereas concern for maternal and child health was viewed as a unique limitation for people living with HIV. Several male respondents explained the latter by articulating that women living with HIV are in a strange state “between life and death” and that their immunity should be protected rather than harmed. Men cited hospital health workers as the source of this idea.

The majority of male respondents perceived that people living with HIV experience more pressure to use family planning than their HIV-negative counterparts. Most men specifically connected use of antiretroviral drugs to a sense of heightened pressure to use family planning. Several men talked about this pressure differential in terms of freedom:

*F: Is there a difference in the way people with HIV and people without HIV feel about using family planning methods?*

*R: There is a difference because someone who has HIV always thinks about using family planning methods, while someone who does not have HIV has the freedom to continue having children.*

-Male MPC FGD 1

*A person who does not have HIV and is not on ART never thinks of anything and is never afraid when doing things because he knows he is okay, but someone who is on ART is always afraid of doing things. He even has negative feelings about proposing to another woman because he knows that if he does that, he will probably cause other problems in his body, while someone who is not taking ART and doesn't know his future is never afraid when doing things.*

-Male MPC FGD 2

All men thought that couples can not be forced to use family planning and that ultimately, each couple should make decisions about contraceptive use based on their own needs. A few men asserted that people living with HIV do not experience increased pressure to use family planning.

Nearly all men thought that family planning is most relevant for spacing births. They explained how they are told at the hospital that babies need to breastfeed for six months to two and a half years (depending on HIV status) and that pregnancies should be spaced accordingly. However, the concept of preventing pregnancy altogether was viewed as dangerous within marriages, as each new marriage carries the expectation of producing at least one child. Some men thought that the absence of children in a marriage renders the union unstable, as childless men often leave their current partners to seek children outside of their marriages. These men thought that women fear divorce and would get pregnant to secure their marriages.

*But if a woman is married, it is uncommon for her to prevent pregnancy because she thinks if she does not get pregnant, she is giving her man a chance to get someone else pregnant.*

-Male MPC FGD 4

Nearly all men felt that family planning is a tool to protect children's futures. They feared projecting their financial and health problems onto their children, which they believed was preventable by investing energy and resources into a smaller family. Several male participants compared investing in family planning to investing in children:

*When you are using family planning, you plan well for your children's education because you have more time for them. As a result, they succeed in school.*

-Male LH FGD 2

Most men discussed the idea of preventing pregnancy altogether within the context of HIV-discordant or concordant-positive marriages. Most men believed that husbands are responsible for advising wives to go (to a facility) for a particular family planning method. The popularity of family planning methods seemed to be age-dependent for most men; younger couples were more interested in using reversible contraception, while older couples were more interested in using irreversible contraception.

There was a variation in how women perceived decision-making around contraceptive use. While most men discussed the issue of HIV-positive pregnancy in terms of a societal obligation, a female respondent specifically blamed men for enforcing the expectation that all new marriages require children:

*It will be a man who will tell you to have a child because it will be a new marriage.*

-Female MPC FGD 1

However, one woman contradicted the belief that men control family planning use by insisting that women are the primary decision-makers when it comes to pregnancy prevention and that "the man agrees hesitantly after you have insisted" [on using a contraceptive method]. Several women added that other family members, particularly mother in laws, weigh in with advice about family planning:

*My mother-in-law told me not to use birth control methods. She wanted me to have many children because, 'in my family, all the people died, and now it's high time you replace them. Don't use the injection method of birth control because this method kills all male children in a woman's womb.' And I told her that I will not bear another child.*

-Female LH FGD 2

One woman challenged the culture of childbearing within marriage, asserting that the foundation of marriage is love, which is defined by more than just children:

*'Love' does not necessarily mean having children. Love exists between two people. Take a couple that has gone for tubal ligation that is still married - they will spend the rest of their lives together, meaning 'love' is more than just children. These are my views.*

-Female LH FGD 4

Another female respondent thought that “mistreatment of women” by their partners encourages women to use family planning.

### ***Cultural Shift***

In four (of eight) of the men's discussions and one (of seven) of the women's discussions, respondents spontaneously compared and contrasted traditional and modern culture around family planning in their communities and country.

In one group, men discussed their modern role in sexual and reproductive health, an area previously considered exclusive to women. One male respondent described men's emerging role in sexual and reproductive health as mandatory, rather than voluntary, to the point that it affected women's ability to seek medical care.

*F: Women say that men refuse to go with [them to the] antenatal clinic, isn't that true?*

*R: That could be a lie because sometimes what they discuss there is secretive, but as things are now there are no secret issues. For example, if the woman is due, the man should be there in the labor ward to wait for her to let him know how important it is to feel for the woman when it comes to issues of family planning.*

*F: From your knowledge, do you see men escorting their wives to antenatal clinics here in Lilongwe or Malawi as a country?*

*R: It is happening.*

*R: I have been there. When she came she was told that she should bring her husband or else she would not be tested.*

*F: It's evidence that such things are really happening and we should expect that to continue happening in the future?*

*R: Yes, that will be happening.*

*R: That has happened to me several times.*

-Male MPC FGD 3

There was a variation in how respondents explained the evolution of family planning. Several men held modern agricultural challenges accountable for competing with couples' fertility desires. They expressed concern about food security as it relates to family planning in both rural and urban areas of Malawi. One man felt that couples' reproductive freedom is threatened by a lack of agricultural resources, so much so that couples have no choice but to use family planning:

*Especially nowadays, everyone is forced to use family planning. Why? Because in the past our parents had children the way they wanted because they used to have more land, which they cultivated, and food was not difficult to find. But now, even in the village, there is a scarcity of land to cultivate, and food is scarce. Even here in town, food is also scarce, so everyone is forced to use family planning and have a limited number of children that one is able to feed and support. Whether one is HIV positive or not, everyone is forced to use family planning.*

-Male LH FGD 1

Another man voiced distrust about modern contraceptive methods because of their association with Western technology. Specifically, he frowned upon modern family planning masquerading as something new, despite being adapted from

natural family planning methods. He also expressed resentment about another culture overlaying its ideas on Malawian society.

*R: I feel like there is nothing good about these [contraceptive methods] because, like I mentioned, I have children. I feel Malawi is busy with technology issues when we have our own ways as Africans.*

*F: Would you explain what you mean?*

*R: We have our own natural methods, which we can use. Like there are some leaves and herbs from which they make a string-like thing, and they tie it around women's waists and tell her she can have sex with her husband, say for seven or ten years, without having a child. But if you decide to have another child in the process, then you untie that string. If I am wrong, this one will correct me because he is of age, and he knows what happens in the villages. So when you untie it and you have sex, she becomes pregnant on the spot. These white people are using our own natural methods and modifying them. It's not that our parents were not practicing family planning - they were using that [natural methods].*

-Male LH FGD 1

Another male respondent attributed modern widespread family planning use to shifting cultural norms around age at first marriage. According to him, young people are prematurely getting married and subsequently delaying childbearing using contraception. He viewed this cause and effect as problematic:

*Family planning is new. There was no such thing in the past because sometime back, people would marry after reaching a good age. But now the problem is that people are getting married before they reach marriage age, and that is what is contributing to family planning [use].*

-Male LH FGD 2

### ***Men's Roles in Family Planning***

While most men believed that husbands should advise wives on family planning issues, several men felt that family planning was women's business. These respondents described men playing passive roles rather than active roles in matters of family planning; they thought those best suited to evaluate issues related to

contraception were those who used contraception (e.g., women, as condoms and vasectomy were the only methods used by men according to the respondents). However, many male respondents elucidated that men do influence their partners' ability to use contraception.

Several men felt uneducated about family planning issues. Further, they did not feel welcome in places that formally shared information about contraception. One man believed that men's exclusion from family planning education programs was problematic because issues are only of "public concern" when everybody is included in analyzing them.

*F: Alright. So where do we learn these family planning issues?*

*R: I believe as men, there is nowhere we learn these issues. We just watch it happening because it seems only women are encouraged to use it, so they learn about it from under five clinics.*

-Male MPC FGD 3

Other men felt frustrated that their knowledge of family planning issues was limited to their partner's experience with contraception. One man also discussed gender norms around communication:

*F: Among the methods which we have mentioned, which ones do people like and dislike?*

*R: It's difficult to respond to that question because each one of us will say what our wife uses, but if it were the man who was using [family planning], it would not be a problem. As a matter of fact, women are better off sharing issues than men because men, we don't share issues...*

-Male MPC FGD 3

One man believed that those who physically bear children (i.e., women) have the right to choose which contraceptive methods to use, and male partners should

simply provide moral support. However, the language used implies that wives are supposed to still consult husbands before acting on their decisions:

*... but you are just there to give her a go-ahead on the method that she has decided to use. A man cannot choose a method for her - the one who can get pregnant has the right to choose which method to use, and you just [support her].*

-Male MPC FGD 3

Another male respondent emphasized that male partners are largely responsible for dissuading women from using family planning. According to him, men dangle the possibility of irreversible infertility as an outcome of using contraception over their partner's heads:

*Even men, we are on the forefront of discouraging women from using family planning. We tell them, 'My wife, you want to use family planning? If you want to do that you should know that you will not have children again.'*

-Male MPC FGD 4

Most women alluded to men's reservations about using contraception, focusing largely on negative side effects and concern for their partner. One woman, however, attributed men's negative interference with family planning to their possessive and controlling attitudes toward women.

Another woman explained that childless couples are often exposed to family planning information too late (i.e., when the woman is already pregnant and presenting for antenatal care). Therefore, couples cannot plan for the birth of their first child.

*F: You are saying that when you are pregnant, they tell you to come with your partner when going for your antenatal care, but assuming there is no pregnancy it means there is nowhere he hears family planning issues?*

*R: When there is no child, even you the woman, you have nothing to do with family planning issues.*

-Female MPC FGD 3

### ***Permanent Methods of Contraception***

All men viewed one partner undergoing vasectomy or tubal ligation without the other as dangerous because of the irreversible effect these procedures have on fertility. According to respondents, this often leads to regret and conflict within marriages. Namely, it creates an unequal power distribution in relationships, whereby fertile partners hold power over infertile partners because of their potential to leave the marriage anytime and to establish a new marriage (and produce children):

*... it was mentioned that it is not only a woman who can prevent pregnancy by going for tubal ligation, even a man can do that. I feel there is a problem there because when you are doing that you do it out of love. You find the man has gotten a [vasectomy] and the woman has not. After two or three days, you find that the woman has run away from her husband, and the man is left alone, but has no more strength to enable him to marry another wife (laughter). Again a woman can go for tubal ligation, and later, the man divorces her. Then another man comes to propose to her, and they start staying together as a family. Then later, the man says, 'I want a child.' When the woman says, 'I went for tubal ligation when I was with my first husband,' and this man says, 'Do you want me to stay childless? Then I am going,' he leaves her.*

-Male LH FGD 1

All men thought that it was better for both partners to be on the same page mentally and physically when using family planning. The respondents believed that both partners undergoing irreversible surgical procedures is less problematic than one partner doing so:

*R: A woman alone cannot go to the hospital for tubal ligation because she thinks that if I do that, this one will leave me and marry another one when he wants to have a child. She would love it if both of you went together so that you should all stop having children.*

-Male MPC FGD 2

*Doing that is like heading your problems together (kutengera phewa limodzi) because if your partner is using an injection and then you use condoms in addition to that it shows you are doing things in one accord and that's the decision you chose to follow.*

-Male LH FGD 2

### ***Independent and Covert Use of Contraception***

Most men expressed that one partner's use of contraception without the other's awareness is often perceived as threatening to the marriage, given its tendency to arouse suspicion about infidelity.

*F: When you look at these family planning methods for both men and women, do you think they are adequate for your needs?*

*R: These methods are enough depending on what you have agreed in your family.*

*F: What do you mean by that?*

*R: You agree - you and your wife - to go to the hospital to 'help us stop having children.' And when you do that, you don't suspect one another in any way, unlike when one does that and the other remains - there is too much suspicion on one another.*

-Male MPC FGD 2

Several men also felt threatened by their partners independently engaging with family planning issues. One man discussed how male exclusion from reproductive health education leads to insecure marriages:

*It would be better if it was through the discussions like we are having now ... it would be good if it was live as we are doing now because people would be given a chance to ask questions or couples would openly say my husband refuses me to use family planning or the man would say my wife's relatives want us to have many children so when you learn such things together you are able to remind*

*one another. If only one person goes to learn of such issues if she comes home and try to apply that the man would say no, that marks the end of our marriage, I will go and marry another wife.*

-Male MPC FGD 3

Most women indicated that when men do not condone their wives' use of family planning, female partners often go against their husbands' wishes and pretend to take their children to under-five clinics where they covertly seek [non-visible] long-acting reversible contraception:

*R: ... you use your own style because there are men who refuse to use family planning. Yet, when he is refusing your own use [of family planning], he is violating your rights. He wants you to be having children without spacing, but doing that it means you are wronging your children. He is violating your rights because at some point that man will run away from you, and you will be the one who face challenges to take care of [the children]...*

*F: I like the words that you said, 'using your own style'. Will you explain what you mean?*

*R: What I mean is ... if the man is telling you not to use family planning when you are going to under five clinics, you use family planning without him realizing.*

-Female MPC FGD 2

Some women relayed that men feel that their role as breadwinner should grant them childbearing decision-making privileges. In these situations, female partners often covertly seek contraception:

*F: Do you think a man's decision also influences whether a family planning method is used or not?*

*R: There are some men who refuse to use family planning, and there are some who accept it.*

*F: In that case, would we say a woman may use family planning after getting consent from her partner?*

*R: Yes, because there are some men who say, 'Don't use family planning. Are you the one who feeds the children? Let's just continue having children,' and I feel like such men do not wish you well because it's not good to bear children without spacing, and neither is it good to have more children.*

*F: Meaning, for a woman to use family planning, a man plays a role? It's not possible for a woman to just make a decision on her own to start using family planning?*

*R: No.*

*R: Sometimes it's possible. You just sneak out, in trying to protect your life.*

-Female MPC FGD 4

Another woman suggested that men use pregnancy to control their partners, thus opposing contraception:

*R: Men always want you to be having children without spacing, fearing that when you look like a young girl other men out there will be proposing love to you. So they continue to get you pregnant - to keep you looking shabby and shabby, then he continues doing whatever he wants.*

-Female MPC FGD 2

### ***Family Planning Acceptability***

One respondent believed he was speaking for all people living with HIV when he said that he developed more positive feelings about family planning after being diagnosed with HIV. While nearly all men thought that family planning is important for their children's futures, this man also discussed its value to economic development in both the household and nation.

Most men conveyed that they and their wives favor contraceptive methods that are longer lasting. For this reason, injectable methods, which are received every three months, were preferred over birth control pills, which are taken daily.

All men voiced their frustrations and fears about side effects of contraception. They were most vocal about criticizing hormonal methods, including birth control pills, injections, and implants. Men critiqued birth control pills for

causing irregular menstruation, abdominal pain, fibroids, and skin rashes on newborns. Injections were said to cause irregular menstruation, weight loss or gain, loss of libido in women, and loss of “taste.” Implants were faulted for causing numbness.

*F: It seems here we are only dwelling on concerns that women have. What about men - do men not have concerns that if their wives use family planning it's gonna [sic] be like this or that?*

*R: The only concern for men is that which we are saying. If a woman uses family planning, say an injection, when you want to have sex with her you argue.*

*R: Yea, because what happens is that she does not have feelings for [sex], yet you are willing to do that.*

-Male MPC FGD 1

*My wife doesn't taste good because of the injection. I feel good when my wife has not used an injection but when she gets that I don't feel good.*

-Male MPC FGD 2

One man also thought that injections cause inflammation. Cervical cancer, permanent infertility, and death were feared to result from using contraception in general, although most men admitted that they had only heard rumors about these side effects. There was consensus that evidence was more influential than hearsay when conducting personal risk assessments related to contraception. Additionally, the respondents were in agreement that they could not use a contraceptive method that would result in increasing their viral load. Some respondents thought that all men disliked using contraception, while others disagreed. Nearly all men considered their partners' problems their own problems:

*But both of you are affected because if the woman becomes sick, her sickness affects you as well, and you become sick too because of the support you give her to make sure that she recovers. Instead of going to work or doing other things you become busy with her sickness.*

-Male LH FGD 1

All men thought that cost and distance to family planning facilities were not barriers to accessing contraception unless one lived in a rural village. Cost and distance could, however, be trade offs given that family planning services in public hospitals and clinics are free, while family planning services in private hospitals and clinics are for fee, but may be more efficient. Respondents thought that village residents were more vulnerable to experiencing cost and distance as barriers to access contraception:

*F: How would you want these family planning methods improved for you?*

*R: There is a need to establish more clinics in the villages.*

*R: I feel like there should be some branches in the villages where people can learn about family planning and be able to choose by **himself**<sup>3</sup> which method **he** should use.*

*R: Establishing clinics in the villages or [sending] other health workers to the villages to provide such services can be helpful because some [people] probably travel about forty kilometers or more to a facility. Some fail to access such services so if you can go there with [family planning] messages, people can utilize that.*

-Male LH FGD 2

Most male respondents approved of the family planning information dissemination strategy used by health communications personnel; one man warned that separating the information by HIV status could be dangerous for people living with HIV.

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<sup>3</sup> The male respondent's use of masculine, rather than feminine, pronouns here is interesting. It indicates willingness for men to be clients of family planning themselves.

*F: Do you think that is good, or you would prefer them to separate it?*

*R: No, that is good. They should not separate it because doing so would mean discrimination.*

*R: If there has to be a separate message, then it should be provided here at the Lighthouse. But when the message is going to the nation, it should be one. If there are other issues, we have to hear them, say in a group like this one when we come here. But separating the message right from the radio, people would know right away that this is the group with HIV, and that can encourage discrimination.*

-Male MPC FGD 3

All men thought that the current family planning methods were adequate, despite no method's 100% guarantee. Some women felt that product stock outs were more worrisome than product adequacy and that they often result in unexpected pregnancies.

Several women criticized contraceptive methods that required regular visits to health facilities (e.g., injections) for intruding on their work lives to the point that they could be fired from their jobs.

Nearly all women emphasized the importance of menstruation and disapproved of family planning methods that interfered with the process.

*When you are menstruating, especially [those of] us who have HIV, we feel better. We feel like we are adding more days to our life - that menstruation removes other bad things in the body. It's the same with someone with HIV or who is negative.*

-Female MPC FGD 1

*... it means you are not responding well if you are not menstruating. Where does the blood go that is produced if you are not menstruating?*

-Female MPC FGD 4

Several women blamed loss of libido and partner infidelity on the injection's side effects:

*F: Alright. Do men and women feel the same way or differently about using family planning?*

*R: It is different because most men refuse most of the time.*

*F: Why?*

*R: Most men hate family planning methods because when women use the injection, when you have sex they get affected with drugs used in the injection.*

*R: Others mention that if the woman is using an injection, she is never sweet like she was before. They say the sweetness is carried away with the injection (laughter).*

*R: They say you taste like water.*

*R: And they say you don't have sexual feelings.*

*R: Even if they touch you, you never get aroused like before when you would get aroused just by a single touch. But when you use an injection, even if he touches you, you are just cold.*

*R: And that's the reason why they chase other women.*

-Female MPC FGD 1

### **4.3 Pregnancy and Antenatal Care**

#### ***Fear of HIV-Positive Pregnancy***

All male respondents believed that fear of transmitting HIV to one's children during pregnancy is universal among women living with HIV. Most men emphasized that women's primary concerns are their children's health and futures and that their secondary concerns are social stigma and bullying within their children's peer groups. One man believed that when a woman is pregnant and taking antiretroviral drugs, her partner should avoid extramarital relationships with women who are not also taking antiretroviral drugs because doing so could increase the risk of transmitting HIV to the baby. Another man thought that HIV-discordant relationships in which the male partner is HIV-positive are more dangerous than the

reverse (in which the female partner is HIV-positive) because he perceived there to be a greater risk of transmitting HIV to the baby in the former situation.

Many men were vocal about women's fear of compromising their own health with an HIV-positive pregnancy. These respondents believed that women living with HIV feared progression of their own disease and even death from simultaneously navigating HIV and pregnancy.

*R: When women are pregnant and HIV-positive they think about the delivery of the child - whether it will be a normal one or whether they will die in the process, because they consider this disease the most dangerous ... which can lead to death.*

...

*R: Yes, they fear they can die because they are pregnant and have HIV at the same time.*

*R: I also hear that when she is pregnant and has HIV, when she goes into labor she can deliver normally, but the disease does not leave her; instead, it progresses. It's like she has caused another illness, so when she comes from [labor] she falls sick again.*

*R: Just to comment on that it is true that when she is pregnant during labor she loses more blood and is likely to experience problems, becoming sick frequently.*

-Male MPC FGD 1

One man had received family planning information for people living with HIV that claimed that children "suck together with the virus," or easily become infected in the womb, and that it is for the best to avoid pregnancy when living with HIV. One respondent shared the idea of testing women's immune systems prior to being given a go-ahead by a health care practitioner to get pregnant while HIV-positive. Another respondent added that he thought male partners' immune systems should also be checked alongside those of their female partners. Many male respondents

thought that an “unhealthy” physical appearance of a mother and baby spreads fear of HIV-positive pregnancies.

Another man sensed that there is a disparity in access to antenatal HIV counseling and testing services between mothers with different birth locations (hospital or home) and mothers with different birth attendants (medical or skilled):

*Those with HIV may be using the hospital because nowadays women who are pregnant are given a privilege to go for an HIV test to know their status, while those who use traditional birth attendants can deliver two or three children without going for an HIV test, and it is difficult for them to have access to HIV counseling and testing.*

-Male LH FGD 2

Several women framed their discussions about fear of HIV-positive pregnancy in terms of employers’ hesitations about hiring people living with HIV; the hesitations were perpetuated by an underlying fear that others’ children may be infected in addition to one’s own child. There was consensus among one female focus group that their main concern as women living with HIV was transmitting the virus from one generation to another, and so forth, affecting families, communities, and the nation:

*R: If we continue having children, it means we will be increasing the viral load. At the same time, our children will also transmit [HIV] to their children, and that means the virus will never be put to end, it will still be there.*

...

*R: The main concern is the HIV because you know it will be like a chain. If you have a child now you will transmit to him, and if you happen to have another child, you also transmit that to him.*

...

*R: What we are considering is that if we continue to increase the number of people living with HIV, we will be putting pressure on the government to struggle to buy us drugs.*

-Female MPC FGD 1

*If you're HIV positive, it's not good to get pregnant because a child can be born with the virus. Hence the child will be sick and sick again. This will in turn bring more worries to the mother. And the mother's health will not be good because of worries.*

-Female LH FGD 2

Despite having witnessed many women living with HIV give birth to HIV-negative children, one woman still feared transmitting the virus during pregnancy. Another woman asserted that women who are taking antiretroviral drugs are perceived as stronger and healthier and thus better situated to have a baby than women who are not taking them.

### ***Undesired Pregnancy and Abortion***

There was disagreement about the availability of safe abortions in Malawi. Most male respondents believed that women in Malawi do not have the option of terminating their pregnancy. They cited a lack of abortion providers, a religious belief among Malawians that abortion is murder, and fear of death from traditional abortions as evidence that women with undesired pregnancies have little control over their situations.

*R: She was not prepared to get pregnant - she is pregnant by accident. What is it that encourages her to continue with the pregnancy? Well, in the first place we should say there is nowhere they say, 'If you get pregnant when you did not want to, you can come here and eliminate it,' so there is no choice. If she is pregnant, then she remains pregnant ... There is nowhere they can go to eliminate it. If there were such a thing they would have been doing that. That is what I feel.*

*R: To add to what he has said, it is a belief people have that eliminating a pregnancy is killing. We have a belief as Malawians that eliminating a pregnancy is killing, so if someone believes that if she terminates the pregnancy it means she has killed - if she is pregnant and she does that it means she has*

*killed - she has sinned against her own belief. When she thinks about this, the end result is she does not terminate the pregnancy. But I believe someone who does not have this belief, she can go to the Lighthouse - I mean at Banja La Mtsogolo (BLM) - I believe it's possible there. It happens, so it depends on what one believes if she has unexpected pregnancy.*

-Male MPC FGD 3

A few male respondents, however, talked about safe abortion as an action that a couple living with HIV could take together to terminate a pregnancy and consequently prevent vertical transmission of the virus. They emphasized men's role as decision makers in these complex situations; according to them, men influence (and even control) the outcome of unwanted pregnancies.

*F: A woman is pregnant when she did not want to be, but she keeps [the baby]; what encourages her to keep that pregnancy?*

*R: It might be because of the man that she is living with.*

*F: He is the one who influences that?*

*R: Yes because the woman tells him, 'I am pregnant,' and that's where a decision has to be made. If you accept that the woman should keep that pregnancy, she will keep it. But if you refuse and say she should go for abortion, then she can do that.*

*F: It's not possible for her to argue?*

*R: No, it's not possible. You are the one to make that decision. If you decide that she go for abortion, she will ask you to give her money, then she will take the money and go for the abortion.*

*R: They do discuss problems that she can experience, one by one, and when she learns that there is going to be a big problem, she understands that and consents to abort.*

*R: Again, before she aborts you and your partner need to go to the hospital so that this can be sorted out by the health workers.*

-Male MPC FGD 1

A few other male respondents asserted that women do have decision-making power over whether to keep or abort their pregnancies. These men believed that a male partner's presence and participation in the pregnancy and the availability of

counseling coupled with a biomedical intervention to prevent transmission of HIV to the child motivates a woman to decide to go through with an undesired pregnancy.

When asked whether it is more frightening to transmit HIV to one's partner or to have an unexpected HIV-positive pregnancy, there was consensus among members of one male focus group that it is more frightening to transmit HIV to one's partner. They referenced the availability of health care personnel to advise HIV-positive pregnancies on preventing transmission of the virus to the child as their rationale. Another male focus group shared different perspectives:

*F: Which is [more] frightening to you - transmitting HIV to your partner or your partner getting pregnant when she did not want to?*

*R: Both.*

*R: Both of them are frightening because she has gotten pregnant when she did not want to, and then the woman might say, 'What should I do now that I am pregnant when I am HIV positive?' Then she finally decides to commit suicide because she doesn't know how she can protect herself if she has never received any type of counseling.*

*R: Did you ask which is more frightening?*

*F: Yes.*

*R: I would like to say the most frightening is getting pregnant because, like I mentioned, when we adults have been diagnosed with HIV we easily understand the situation and we continue with our life, but if my child is born with HIV, it's something that gives you worry because you know that when his friends realize his status, he will never be at peace. And you force the child to be taking drugs when his friends are not also on drugs, [and that] makes him question himself ... So which is more frightening: getting pregnant because that child will have HIV like its mother - she is positive.*

-Male LH FGD 3

Most participants attached different meanings to being an HIV-positive child versus adult; they asserted that children's physical *and* mental health could be harmed by having to navigate serious health issues early in life.

One female respondent remarked that women have less control over their life circumstances than men. She applied this idea to her explanation that women must be flexible when they experience an unwanted pregnancy.

*R: ... as women, we are flexible. [We] easily accept situations that come in life. When a situation comes, we are able to accept it. As an HIV positive woman, when you are telling a husband that you are pregnant, your husband is not able to accept it. He tells you that it is none of his concern. As a woman, you have no option. You just accept it because you get worried about losing your life through abortion.*

*F: Men say that it is none of their concern?*

*R: Yes.*

*F: I thought they are the one responsible for the pregnancy?*

*R: It is not easy for them to accept, but as a woman you accept it.*

-Female LH FGD 1

One woman remarked that, "If your partner is caring he escorts you to the antenatal while others they just tell you to go by yourself" (Female MPC FGD 1).

### ***Dissemination of Information***

Knowledge of counseling along with a biomedical intervention to prevent mother-to-child transmission of HIV was universal among participants. However, several male participants expressed frustration with the government and public health practitioners for disseminating unclear and contradictory information regarding childbearing to people living with HIV.

*R: Information that says, 'When you are HIV-positive you can have children' is not coming out clear. They say you can have a child, but there is a chance that the child will be born HIV-positive .... by the time you realize that the child is positive you cannot go back, and that gives us a feeling to say, 'Should I have a child or should I not have a child?' because [if] that child is born HIV-positive it cannot be reversed. So to make a decision whether or not you should have children is difficult since chances are fifty-fifty. If they would possibly say, 'Once you follow this, the child will be born negative,' it would make you feel okay.*

*But when you are not assured, you don't feel quite flexible so you are not able to make a decision because you live in doubt. So there is an information gap there.*

*F: So you are saying the information is not coming out clear?*

*R: It is not clear. They need to say, 'When you do ABC you get this, or when you do ABC you maybe get this or that way.' You see? So that when you are doing things you should know that the baby can be positive or negative, but when it is positive, you cannot reverse it. If it is positive it means it will be worse once and for all. But you will find the information [saying] 'It is all up to you.' Then you wonder, you say, 'It's up to me?' That gives you worries, and to make a decision is always difficult.*

*R: Information is not coming out specific to say, 'It is better that you should not have children.' Or the information is not specifying, '80% of the time you should not have children,' because the way I see it, I feel the chance that you transmit HIV to the child are very high. As a result, you find a woman saying, 'I want to have a child,' because here she has been told that she can have children. While on the same [topic], someone might feel, 'If I have a child, I can transmit HIV to the child (compared to the information that says the baby can be born HIV negative). So it is not coming out clearly whether we should have children or not.*

-Male MPC FGD 3

These men conveyed that they do not feel safe to make childbearing decisions within an HIV-positive context because they cannot trust the information being presented to them by the government and public health practitioners. They seem to desire a level of certainty about the outcomes of HIV-positive pregnancy that does not exist. Of particular concern were the informational changes about mother-to-child transmission of HIV through pregnancy and breastfeeding practices for HIV-positive mothers over the past two years; these men felt that they are being sent mixed messages about their safety.

*R: ... things have just changed in the past two years. They were saying if you are a positive mother you will have a positive child, but now they are slightly changing that. They say the child can be either HIV-positive or negative, which is not specific.*

*F: It was specific at first?*

*R: It was very clear. They were saying a positive mother will have a positive baby, and they would tell [them], 'Don't have children.'*

*R: If by mistake the mother had a baby it was supposed to be breastfed for only six months if she cannot manage to buy milk for the baby, but now they are saying you can breastfeed the child for two years. So people are failing to understand that because they are the same people who were told that they should breastfeed the child for six months, and the same person is being told to breastfeed the child for two years, so it is a bit confusing to people. They are confusing us because we are the same HIV-positive people.*

-Male MPC FGD 3

One man recommended that the Ministry of Health treat information targeted toward newly diagnosed childless couples in a more sensitive way (than newly diagnosed couples with children). Specifically, he hoped the Ministry would spend more time counseling newly diagnosed childless couples in-person because an HIV diagnosis is perceived to be more burdensome on this group of people.

Other respondents questioned the government's basis for changing HIV maternal and child health recommendations:

*R: I feel that if the government gave an okay for people with HIV to have children based on stigma and discrimination - not from research - then it was not a good idea because HIV was known through research. And if they now feel an HIV-positive person can have children - that was also supposed to be based on research because we need to raise up a good generation ... so if the government had to base [its recommendations] on [stigma and discrimination], I feel it was not properly done because this generation will continue to exist. But if it was based on research, then I think it is right that people with HIV can have children.*

*R: Let me agree with this one because the government cannot just wake up one morning and say, 'Because people are being discriminated [against], let us loosen the information and screw some of the things.' It cannot be like that because at the end of the day it must conform to the WHO standards. You cannot say, 'I will do this by myself' because anything that has to happen has to be approved by the WHO. So I believe that a government that loves its people cannot do that, because in the end it will wipe out the whole generation, people will not be there.*

-Male MPC FGD 3

#### 4.4 Voluntary HIV Counseling and Testing (VCT)

##### *Covert and Independent Testing vs. Couples' and Family Testing*

All male respondents believed that while in a relationship, covertly or independently seeking an HIV test is problematic. According to them, this practice raises a red flag in relationships that the partner who seeks testing may be untrustworthy. When asked how they would break the news of testing positive to their partners if they had covertly sought testing, most men responded that they would suggest going to get tested with their partner rather than reveal that they had gone alone.

*R: You cannot just go and introduce the topic in an open way. You try to think twice yourself and withdraw before you have even raised the issue. If you tell her, 'I went to the hospital, and my status is this or that,' she will not respond to you immediately. She can just say, 'Oh okay,' but she will still be thinking it over.*

*R: She even starts suspecting you.*

*R: She might be faithful on her end, and now she can start suspecting that you are promiscuous. She can think a lot about you, and if you can ask her, 'Are you not going for a test yourself?' she can say anything.*

*F: So the best way is to go together - with her?*

*R: The best way is to go with her, that's all.*

*F: How do you look at it, sir?*

*R: I feel it's better to go together, man and woman for an HIV test.*

*F: Would she not suspect you when you say, 'Madam let's go for a test?'*

*R: She will not suspect you if the wife is trustworthy.*

-Male MPC FGD 1

Most men felt that a third party delivering the message buffers receiving negative news about a partner's HIV status. According to them, those who are blindsided by such information (when communicated by their partners) are more likely to experience a closed-minded reaction that may result in serious consequences for the relationship.

*F: How would someone introduce this issue? Let me give my own example. I went to the hospital to have an HIV test but I did not tell my wife. They have diagnosed me HIV positive. Now how would I introduce this to my wife when we are in the bedroom, just the two of us?*

*R: If you just introduce it any way, she may react on the spot and tell you, 'We will not have sex, and this marks the end of our marriage.'*

*R: It should be a time when you have eaten your food and are prepared to go to bed. Then you look at the mood that your wife is in. You can tell that telling her this issue without preparing her she will react. So as my wife, I need to tell her that, 'Madam at some point when we have time, we should go to the hospital to get an HIV test. We will go together.' And that is before you tell her that you had already gone for testing.*

...

*F: You feel if she hears that from the hospital it will be easier than telling her yourself?*

*R: Yes.*

-Male MPC FGD 2

Most men viewed covert or independent testing as harmful and couples' testing as protective to a relationship's future. They believed that participating in couples' testing strengthens relationships because both partners work together.

*F: ... Assuming that you just sneaked out of the house and went for an HIV test and you have been diagnosed HIV positive, how would you tell your partner?*

*R: You can just tell her, 'My wife let's go for an HIV test.'*

*F: Oh, you would suggest going together?*

*R: Yes.*

*F: When you know you have already been tested?*

*R: Yes (laughter).*

*F: What if she asks you why?*

*R: I can tell her, 'We should know our HIV status in order to plan for our future well instead of living ignorantly.'*

*F: Yet you know deep down in your heart that you have already been tested HIV-positive?*

*R: Yes (respondents laughing).*

-Male MPC FGD 4

One male respondent shared with his group that after he and his wife got tested for HIV and made decisions about family planning together, their sexual and reproductive health problems faded. Another man conveyed that a partner's

reception of unfavorable news could be impacted by their sense of being needed and actual participation while seeking medical attention:

*R: ... he is trying to say there are different situations. For example, if I am sick at home and, assuming that I have come to the hospital, my partner has escorted me, and there I happen to be diagnosed with HIV, my partner cannot feel very disappointed. But if I am fit, I just go home and go straight into introducing the issue. There can be a big problem.*

*F: Oh! If she hears [your status] from the hospital after escorting you, that would not be a problem for her?*

*R: Yes, she can easily handle it.*

-Male MPC FGD 4

Another man advised his group that upon testing positive for HIV as a parent, all children should be tested for HIV as well.

One woman shared that men usually “sneak out by themselves and go for an HIV test without telling you.” She added that when both partners know their HIV status they can discuss their future as a couple. Most female respondents considered getting tested for HIV as a moment of truth in relationships – the results allow a couple to either take their relationship to the next level or end it:

*You start discussing it in a relationship. You say, ‘I know you have loved me, and before marriage we need to go for an HIV test so that we should know our statuses and see the way forward.’*

-Female LH FGD 1

### **Communication**

All male respondents suggested that frank communication with partners and community members about HIV testing was important to relieve personal and inter-personal stress related to HIV. One man recommended that if one partner were to

seek HIV testing without the other partner for logistical reasons, then s/he should communicate these intentions to her or his partner beforehand. This would allow both partners to mentally prepare for the results and the decision-making that would follow suit. Additionally, it would respect both partners' stakes in the relationship.

*... you should be open because the [burden] that you carry is not just yours - it can also affect your child or your partner, and [your partner] can make a decision to go for an HIV test as well.*

-Male MPC FGD 4

One man discussed changing norms regarding HIV status awareness, and another discussed the issue of disclosure of HIV status as it relates to the practice of divorce:

*R: Again, it is because of the women that we know about HIV because, nowadays, there is a system whereby every woman who is pregnant undergoes an HIV test. So they are the ones who come to tell us when they have been tested.*

*R: On the same [topic], there are few women who come openly to tell you that they have tested HIV-positive. Most of them are afraid to tell you because they fear their husbands will divorce them.*

-Male LH FGD 1

Another man addressed the issue of peer judgment, specifically within the workplace, by advocating for free communication among workers and community members. Being "open" in the office and in the community was viewed as beneficial for not only the person living with HIV, but also her or his peers:

*When my boss saw that I was not feeling well he told me that we should go to the hospital, and I agreed. He was saying that right in front of other workers, but I accepted to come to the hospital. They conducted an HIV test and diagnosed me positive, and I was open in the office. Everyone at my office is aware of [my status], and I don't hide it. I tell them the truth because*

*sometimes they are the same worries that make you feel sick, even when you are taking drugs, because you think other people are talking about you. But when you are open, everything is put in order ... So when you are taking drugs while you are stressed, you might fall sick. But when you rule that out and become open, even if someone is talking about you, you don't mind because you know tomorrow it might be him.*

-Male MPC FGD 3

### ***Delayed Testing and Forced Testing***

All male respondents considered delaying testing following experiencing initial symptoms of HIV harmful to one's physical and social wellbeing. They suggested that avoidance ultimately led to a loss of independence and privacy because it resulted in more serious symptoms of HIV and consequently, vulnerability and reliance on others to seek medical attention. Most men attributed this behavior to denial and procrastination, and several of them spoke from personal experience.

*... I have a brother who was refusing to go to the hospital, but I forced him. I took the office vehicle and escorted him to the hospital. The first time he went for the test, he tore up all the results papers, and when he was going a second time he was anemic and dehydrated and was admitted. But now he is at least doing fine. So I was telling him, 'It's not good to hesitate. When you are still strong and you feel you are sick, you need to rush to the hospital.'*

-Male MPC FGD 3

One man believed that HIV-related stigma and discrimination are perpetuated by the practice of delaying testing because people experience visible symptoms of HIV in the public eye, generating fear within communities.

*What I see most of the time is that when you are sick, you become the root cause for people to start discriminating, because if you feel sick you need to make a decision to go to the hospital by yourself, but there are some who wait until they are seriously sick, then people come to take you to the hospital. That is what causes fear in most people, but when you feel you are sick you just need*

*to go by yourself. Like in my case, I came here by myself. ... If we take the whole [country of] Malawi, there is no one who can point fingers at someone. If you do, you stay indoors when you experience the same thing, fearing others because he had to point fingers at them. If people tell him to go to the hospital, he refuses until he dies in the house. Why? Because he was on the forefront of talking about other people, so you develop fear to ask others to escort you to the hospital when you fall into the same pit. So sometimes you need to make a decision yourself without minding what other people will say so long as you know the condition of your life. If you feel shy or afraid of others - that they will laugh at you - you ruin your own life because it is very simple. If you start going to the hospital while people are watching you, all the worries go away and you become strong again.*

-Male MPC FGD 3

Several men communicated that delaying testing was by default delaying treatment.

*When we are taking these drugs we stop having worries, because if we look at our friends who are still hiding themselves, they are the ones who are mostly dying and that encourages us more. We feel we made a good decision to go for an HIV test.*

-Male LH FGD 2

One male respondent warned his group about the impact that delaying testing could have on children and parents (e.g., ignorance of one's HIV status could translate to transmission of HIV to one's children and burdening one's own immune system). According to this man, delaying testing may also result in couples having more children than they would have had they known their HIV-positive status.

Several women also talked about getting tested for HIV as a pathway to getting treated for HIV and to condom use.

*... I used to have concerns when I had not gone for an HIV test because I was always getting sick. But when I started taking these drugs, I no longer got sick. So I don't have any worries.*

-Female MPC FGD 4

One woman communicated that she was frustrated with her husband for delaying testing because he does not want to use condoms during intercourse. She feared that he put her at risk because the effectiveness of her antiretroviral drugs could be compromised.

*... It is required for your partner to come for an HIV test when you know that you are HIV positive, but if he refuses you know that your partner is cheating - he doesn't wish you well, and it is the woman who suffers a lot if her partner is delaying going for the HIV test.*

-Female MPC FGD 1

One woman prioritized the issue of forced testing in the workplace and the negative effect that this practice has on employment:

*... The main concern is about issues related to work. I would like to give evidence that I was working somewhere, and my boss took me by force to the hospital for an HIV test. I was refusing, but she took me to the hospital. After getting tested, I was found HIV-positive. Then she told me that I have been dismissed. So we have such concerns when people discriminate [against] us at work.*

-Female MPC FGD 1

#### **4.5 Antiretroviral Therapy (ART) & Antiretroviral Drugs (ARVs)**

Throughout all of the male and female focus group discussions, the facilitator and the respondents used the word “ART” as a substitute for “HIV.” Although these terms were often exchangeable, most respondents seemed to place more weight on being on ART than being HIV-positive alone. They shared practices that could result in unfavorable interactions with ART (rather than with HIV) and talked about ART as an obstacle to sexual and reproductive health freedom (rather than HIV).

### ***ART & ARV Interactions***

Respondents honed in on perceived beneficial and harmful ART and ARV interactions. All male respondents believed that the use of antiretroviral drugs (ARVs) alone is not sufficient to prevent mother-to-child transmission of HIV. They communicated that the practice needs to be supplemented with condom use and additional drugs from the hospital. One man, however, feared that ARVs could be harmful for the baby during pregnancy.

There was consensus among all of the male focus groups that antiretroviral therapy (ART) does not reduce condom use because it is possible for someone undergoing ART to transmit HIV to their partner. One man viewed condoms as a backup tool for people undergoing ART, because according to him, condoms stabilize viral load.

*F: Don't you think these ARVs reduce condom use?*

*R: No because if I have HIV and I happen to transmit it to another person, [the virus] becomes stronger in that person's body and begins to multiply. And that is the reason why they say even if we are all on ART we should be using condoms.*

-Male LH FGD 1

Several men expressed concern about a shortage of companion drugs, such as Bactrim, for ART. They worried that their ARVs would not be as effective without helper drugs.

Others had concerns about ARVs interacting negatively with abortion drugs and contraceptive methods.

One woman expressed disagreement with the rest of the groups' beliefs about ART's impact on condom use:

*F: Do you think using ART reduces condom use for others?*

*R: It is possible because there are other people who become loose because they are on ART; they forget that when you are having sex without a condom you increase your viral load. When you are using condoms and taking your drugs, the virus is weakened, but if you are not, it's always active.*

-Female MPC FGD 1

### ***Use of ART While in a Relationship***

There was consensus among one male focus group that while in a relationship undergoing ART without one's partner's knowledge is problematic:

*F: Alright. Say, for example, you are already on ART but your partner is not aware. How would you let her know?*

*R: When it comes to that it is always difficult. You should not start ART when your partner is not aware of your HIV status.*

*R: When things come to that it is always difficult.*

*R: Like in my case, I had a girlfriend, but she was not aware that I am on ART. The day that I told her things got worse, and since then, I decided to keep that to myself.*

-Male MPC FGD 5

One man communicated that when both partners are on ART, some men become unfaithful:

*... There are other men, when they see both [partners] are on ART, they are never faithful to their partners. As a result, there are always quarrels in the house ...*

-Male MPC FGD 2

Several women expressed concern about men refusing to use condoms when both partners are on ART:

*... it happens sometimes that a woman is HIV-positive and the man too has HIV, and you are all on ART. When it comes time that you want to have sex, you find him saying no to condoms. He says, 'You are on ART, and I am also on ART,' so we are always afraid of that. It's not a wish to be alone ...*

-Female MPC FGD 3

### **ART Acceptability**

Most male respondents expressed positive feelings toward ART, which they credited with restoring health and life, and subsequently productivity and happiness. According to them, although ARVs themselves are a visible symbol of living with HIV, which may often be used against them by peers who stigmatize and discriminate, the physical and mental clean slate that it affords them is worth the reminder. Additionally, these men communicated that they felt like they had the upper hand when being "laughed at" by people not underdoing ART because their health was being restored while their teasers' health was at risk.

*If you went for an HIV test - like when I was diagnosed HIV-positive, I was with some people in the waiting room who also wanted to have an HIV test, and the doctor said, 'If you hear your results, would you not cry or take drugs to commit suicide?' And they said, 'We will not take drugs,' but when they were coming from the results room, they came out crying for their lives as if they were already dead. But I know this is a new life - if we take these drugs and follow the procedure, it's like we are mending our lives. So you need to be open[-minded] when you get home after hearing your results.*

-Male MPC FGD 4

*F: What change are there, if any, in a life of a person taking ART?*

*R: There is a change in the sense that when you are not on ART, you don't feel strong enough to even carry a small thing, or you do not work as you used to. But after ART, you find yourself able to carry the heavy things and work properly. Now everything is going well because of these drugs.*

-Male LH FGD 1

*When you are taking these drugs, your health is restored as it was at first, and you can do anything that any other person who is not HIV-positive can do.*

-Male LH FGD 3

Several men stressed that “swallowing drugs for a lifetime” was undesirable and used this perspective to warn their children about the dangers of HIV. One focus group in particular honed in on this downside of ARVs:

*F: My first question is, ‘What are the major concerns and health issues of women living with HIV?’*

*R: They are always negligent when it comes to taking drugs.*

*R: Most of the times when these women have gone for HIV testing, they become disappointed if they do not welcome the news positively. They do not feel like taking the medicine. But if they receive [the news] positively, you have a good relationship with her, and you even advise her sometimes on drug issues.*

*R: Women do not always follow the drug instructions. They always forget to take the medicine, and they always look angry.*

*F: What do you think makes them angry?*

*R: Because of the disease.*

-Male MPC FGD 4

Half of the men believed that ART has no impact on libido; half of the men believed that it does or can in some cases. One man argued that when sick, the body and mind are not strong enough to engage in or think about engaging in sex. He believed ART strengthens the body and restores libido. However, others argued that ART does increase sexual desire in and of itself. Nearly all men thought that ART does not cause sexual and reproductive health problems for women, such as irregular menstruation or infertility. However, all men either knew someone who had experienced or they themselves had experienced leg or back pain from undergoing ART. These respondents pointed out that most people experienced pain while on ART Starter Packs. Most respondents indicated that when they communicated this pain to at their ART clinics, they were either told the pain would resolve after some time or helped to change regimens. One man was concerned

about a message he heard on the radio about ART users “being attacked with cancer” (Male LH FGD 2).

One woman discussed how adhering to pharmaceutical instructions after initiating ART curbs HIV illness.

*F: What changes are there, if any, for those who are using ART?*

...

*R: Again you no longer have regular sickness because when you have not started the drugs, you fall sick regularly. But once you start taking the drugs and follow their instructions, you never fall sick again.*

-Female MPC FGD 1

Another woman explored the idea of ART initiation being a rebirth:

*F: My first question is what are the major concerns and health issues for women living with HIV?*

*R: In my case, I don't have concerns because since I started taking these drugs, I realized that this is not the end of my life, but is the beginning of another life.*

-Female MPC FGD 4

Most female respondents struggled with the idea of taking drugs every day for the rest of their lives. These women discussed the gravity of being dependent on pharmaceuticals for survival. One woman described her most basic hope for progress with this issue:

*I also feel these drugs should be changed. They should be giving us injections instead, because taking drugs is painful. Of course drugs help us, but it's not good to be taking drugs on daily basis. The injection is better because you can go for some time before getting another one.*

-Female MPC FGD 4

Several female respondents had either heard of others experiencing or they themselves had experienced irregular menstruation while on ART. Many women

also complained of leg numbness while on ART. Most women talked about side effects of ART in terms of physical appearance (in addition to physical feelings). One woman heard that ART caused body deformations and breast growth.

*F: What changes are there if any for those who are using ART?*

*R: There is a change. Let us assume you are being given an [ART] Starter Pack. It makes you sick if you started late, but others respond well, despite some experiencing skin rashes.*

*R: There are some people who start the drugs when their immunity is very low, and in the process, their immunity gets higher, so they look changed compared to how they looked at first. You gain some weight.*

-Female MPC FGD 1

*F: If you were to make suggestions about these drugs, how would you want the drugs improved?*

*R: They should improve the drugs because they give [visible] side effects, which other people are able to see. Such people insult us. You will hear them say, 'Look at her - she is taking ARVs,' all because of her looks, so people talk a lot and that can cause you many worries. So we would love if these drugs were not giving tangible side effects on a person's body. People should have their normal bodies.*

-Female MPC FGD 4

*F: What do you think could be done to ARVs to make them better?*

*R: It's difficult to tell, because the medicine is made by the whites (sic).*

*R: They should remove side effects of the medicine.*

-Female LH FGD 2

## 4.6 Summary Tables

**Table 1A: Summary of Male Involvement and Participation in SRH (Condoms)**

	<b>He Said</b>	<b>They Both Said</b>	<b>She Said</b>
<b>i. Expectations of Condom Use</b>	<ul style="list-style-type: none"> <li>• Condom use is a chronic, life-long personal health practice in response to an HIV diagnosis</li> <li>• HIV-positive (discordant or concordant) couples without any children should be able to have at least one child</li> </ul>	<ul style="list-style-type: none"> <li>• PLWHIV are supposed to use condoms during every sex act</li> <li>• Condoms are the best contraceptive method for PLWHIV</li> <li>• Married couples are expected to engage in unprotected sex</li> <li>• Couples with at least one HIV-positive partner are not supposed to get pregnant</li> <li>• If they do get pregnant, couples with at least one HIV-positive partner should use condoms throughout the pregnancy to prevent spreading HIV to the baby</li> </ul>	<ul style="list-style-type: none"> <li>• Men expect married couples with at least one HIV-positive partner to adhere to society's expectations of condom use, rather than the medical community's expectations of condom use (regardless of HIV status)</li> <li>• Each new marriage is supposed to produce children (e.g., demands unprotected sex)</li> <li>• Condoms are an absolute during HIV-positive pregnancies</li> <li>• Society's expectations of condom use vary by relationship type</li> </ul>
<b>ii. The Meaning of "Protection"</b>	<ul style="list-style-type: none"> <li>• Sex without a condom symbolizes a deeper trust and commitment to one's partner</li> <li>• Unprotected sex is "self-indulgent" for PLWHIV</li> <li>• Women want to have unprotected sex so their partners can demonstrate commitment to them and so they feel safe</li> </ul>	<ul style="list-style-type: none"> <li>• Condoms give people a sense of control in a situation that feels out of their control (e.g., the HIV epidemic)</li> <li>• Condoms function to protect oneself, one's partner, and one's existing and future children</li> <li>• Protection is an act of love (for one's children)</li> <li>• Condom use has a role in securing families, communities, and the country</li> <li>• Society's expectations of condom use varies by relationship type</li> <li>• Protected sex is a</li> </ul>	<ul style="list-style-type: none"> <li>• Unprotected sex is "entertainment" for PLWHIV (contrast with the monotony of protected sex)</li> <li>• Protected sex satisfies physical needs but not emotional needs (lack of intimacy)</li> <li>• For PLWHIV, unprotected sex threatens life</li> </ul>

		health wellness practice	
<b>iii. Promiscuity and Stigma</b>	<ul style="list-style-type: none"> <li>Married women carrying condoms in their handbags in public are perceived as promiscuous</li> <li>Unmarried (NOT married) women are at risk of contracting HIV</li> <li>Finding condoms in a wife's handbag is grounds for divorce</li> </ul>		<ul style="list-style-type: none"> <li>All women should carry condoms in their handbags, regardless of marital status</li> <li>It is easier to remain unhappily in widowhood than to disclose one's HIV status to a new partner</li> <li>Women fear disclosing their HIV status to new partners</li> </ul>
<b>iv. Condom Acceptability, Negotiation, and Partner Refusal</b>	<ul style="list-style-type: none"> <li>Condoms negatively impact sexual experience</li> <li>Women lack power to negotiate condom use during the act of sex</li> <li>Condoms "add" diseases</li> <li>Dual methods of contraception (i.e., condoms plus a backup method) are only necessary if one is HIV-positive</li> <li>Men are negligent and selfish when they refuse to use condoms</li> </ul>	<ul style="list-style-type: none"> <li>Condoms have side effects and are not 100% trustworthy</li> <li>Men have more control over condom use</li> </ul>	<ul style="list-style-type: none"> <li>Men are opposed to using condoms</li> <li>Men say, "One does not eat a sweet while it's in its paper" to get out of using condoms</li> <li>Women are not opposed to using condoms</li> <li>Men threaten to leave their spouses for women willing to have unprotected sex</li> <li>It is sometimes necessary to use a backup contraceptive method without a male partner's knowledge</li> </ul>

**Table 1B: Summary of Male Involvement and Participation in SRH (Contraception)**

	<b>He Said</b>	<b>They Both Said</b>	<b>She Said</b>
<b>i. Decision-Making around Contraceptive Use</b>	<ul style="list-style-type: none"> <li>A couple's financial status and HIV status influence decision-making around childbearing and contraceptive use (particularly men's financial)</li> </ul>	<ul style="list-style-type: none"> <li>PLWHIV experience more pressure to use family planning than their HIV-negative counterparts</li> <li>Couples cannot be forced to use family</li> </ul>	<ul style="list-style-type: none"> <li>Men are responsible for enforcing the expectation that all new marriages require children</li> <li>Other family members, such as mother-in-laws,</li> </ul>

	<p>status and women's HIV status)</p> <ul style="list-style-type: none"> <li>• Use of antiretroviral drugs leads to a sense of heightened pressure to use family planning</li> <li>• Family planning is most relevant for birth spacing</li> <li>• Husbands are responsible for advising wives to go to a facility for a particular family planning method</li> <li>• PLWHIV have less freedom in their sexual and reproductive lives</li> <li>• The absence of children in a marriage renders the union unstable</li> <li>• Women fear divorce and would get pregnant to secure their marriages</li> <li>• Younger couples are more interested in using reversible contraception than irreversible contraception</li> </ul>	<p>planning</p> <ul style="list-style-type: none"> <li>• Family planning is a tool to protect children's futures</li> </ul>	<p>weigh in with advice about family planning</p> <ul style="list-style-type: none"> <li>• Marriage is not defined by children, but rather by love</li> </ul>
<b>ii. Cultural Shift</b>	<ul style="list-style-type: none"> <li>• Men are now escorting their wives to antenatal clinics</li> <li>• Recent agricultural challenges impact couples' fertility desires (i.e., limit them)</li> <li>• Men refute the idea that they refuse to accompany their partners to antenatal care</li> </ul>		
<b>iii. Men's Roles in Family Planning</b>	<ul style="list-style-type: none"> <li>• Family planning is women's business</li> <li>• Women are better suited to evaluate issues related to contraception</li> </ul>	<ul style="list-style-type: none"> <li>• Wives are supposed to consult husbands before acting on their family planning decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Men have reservations about using family planning</li> <li>• Childless couples are often not</li> </ul>

	<ul style="list-style-type: none"> <li>• There is nowhere men learn about family planning issues</li> <li>• Husbands should advise wives on family planning issues</li> <li>• Men are frustrated that their knowledge of family planning issues is limited to their partner's experience with contraception</li> <li>• Men's exclusion from family planning education programs is problematic because issues are only of "public concern" when everybody is included in analyzing them</li> </ul>		<p>exposed to family planning at all</p> <ul style="list-style-type: none"> <li>• Men's negative interference with family planning is attributed to their possessive and controlling attitudes toward women</li> </ul>
<b>iv. Permanent Methods of Contraception</b>	<ul style="list-style-type: none"> <li>• One partner undergoing vasectomy or tubal ligation without the other partner is dangerous; doing so often leads to regret and conflict within marriages</li> <li>• It is better for both partners to be on the same page mentally and physically when using family planning</li> </ul>	<ul style="list-style-type: none"> <li>• Fertile partners hold power over infertile partners</li> </ul>	
<b>v. Independent and Covert Use of Contraception</b>	<ul style="list-style-type: none"> <li>• One partner's use of contraception without the other partner's awareness is often perceived as threatening to the marriage</li> <li>• One partner's use of contraception without the other partner's involvement is often perceived as</li> </ul>		<ul style="list-style-type: none"> <li>• When men do not condone their wives' use of family planning, female partners often seek [non-visible] long-acting reversible contraception covertly</li> <li>• Men feel that their role as breadwinner should grant them childbearing</li> </ul>

	threatening to the marriage		<p>decision-making privileges</p> <ul style="list-style-type: none"> <li>• Men who refuse to let their partners use family planning are violating women's rights</li> <li>• Men use pregnancy to control their partners and are thus dislike family planning</li> </ul>
<b>vi. Family Planning Acceptability</b>	<ul style="list-style-type: none"> <li>• Men and women favor contraceptive methods that are longer lasting (e.g., prefer the injection over birth control pills)</li> <li>• Use of reversible methods of contraception may lead to permanent infertility</li> <li>• A partner's problems are one's own problems</li> <li>• Cost and distance to family planning facilities are not barriers to accessing contraception unless one lives in a rural village</li> <li>• Cost and distance can be trade offs when deciding between a public or private family planning facility</li> <li>• The current family planning methods are adequate</li> <li>• Separating family planning information by HIV status could lead to discrimination</li> </ul>	<ul style="list-style-type: none"> <li>• Contraceptive methods, particularly hormonal methods, have negative side effects</li> <li>• Evidence is more influential than hearsay when conducting personal risk assessments related to contraception</li> <li>• Any contraceptive method that increases viral load must be avoided</li> <li>• Some methods of family planning may cause a change in libido</li> </ul>	<ul style="list-style-type: none"> <li>• Contraceptive methods that require regular visits to health facilities (e.g., injections) often intrude on women's work lives to the point that women could be fired from their jobs</li> <li>• Regular menstruation is important, and contraceptive methods that interfere with it are disliked</li> <li>• Product stock outs are currently a bigger issue than product adequacy</li> </ul>

**Table 1C: Summary of Male Involvement and Participation in SRH (Pregnancy and Antenatal Care)**

	<b>He Said</b>	<b>They Both Said</b>	<b>She Said</b>
<b>i. Fear of HIV-Positive</b>	<ul style="list-style-type: none"> <li>• Women fear</li> </ul>	<ul style="list-style-type: none"> <li>• Women living with</li> </ul>	<ul style="list-style-type: none"> <li>• Women fear HIV-</li> </ul>

<p><b>Pregnancy</b></p>	<p>compromising their own health with an HIV-positive pregnancy</p> <ul style="list-style-type: none"> <li>• HIV-discordant relationships in which the male partner is HIV-positive are more dangerous than the reverse (in which the female partner is HIV-positive)</li> <li>• Both partners immune systems should be checked prior to being given a green light to get pregnant</li> </ul>	<p>HIV fear transmitting the virus to their baby during pregnancy</p> <ul style="list-style-type: none"> <li>• Women are primarily and secondarily concerned about the effect that HIV would have on their child's physical and mental health, respectively</li> </ul>	<p>positive pregnancies because of potential employers' hesitations about hiring them</p> <ul style="list-style-type: none"> <li>• Women fear transmitting HIV from generation to generation, affecting families, communities, and the nation</li> </ul>
<p><b>ii. Undesired Pregnancy and Abortion</b></p>	<ul style="list-style-type: none"> <li>• Most women in Malawi cannot terminate their unwanted pregnancies</li> <li>• In cases where abortion is possible, men are the primary decision makers in these complex situations</li> <li>• Women with undesired pregnancies have little control over their situations</li> <li>• Most Malawians believe abortion is murder</li> </ul>	<ul style="list-style-type: none"> <li>• Living with HIV as a child is more problematic than living with HIV as an adult</li> <li>• A male partner's presence and participation in an unwanted pregnancy may convince a woman to go through with the pregnancy</li> </ul>	<ul style="list-style-type: none"> <li>• Women have less control over their life circumstances than men</li> </ul>
<p><b>iii. Dissemination of Information</b></p>	<ul style="list-style-type: none"> <li>• The government and public health practitioners send mixed messages to the public about childbearing while living with HIV</li> <li>• It is hard to make decisions about childbearing while living with HIV when one feels that health guidelines cannot be trusted</li> </ul>	<ul style="list-style-type: none"> <li>• Counseling plus a biomedical intervention to prevent mother-to-child transmission of HIV is available at hospitals</li> </ul>	

**Table 1D: Summary of Male Involvement and Participation in SRH (Voluntary Counseling and Testing)**

	<b>He Said</b>	<b>They Both Said</b>	<b>She Said</b>
<b>i. Covert and Independent Testing vs. Couples' and Family Testing</b>	<ul style="list-style-type: none"> <li>• While in a relationship, covertly or independently seeking an HIV test is viewed as problematic; it raises a red flag that the partner seeking testing may be untrustworthy</li> <li>• If men test positive when seeking covert testing, they suggest that their partner accompany them to be tested together rather than reveal the results themselves</li> </ul>	<ul style="list-style-type: none"> <li>• A third party delivering the message buffers receiving negative news about a partner's HIV status</li> <li>• When both partners know their HIV status they can plan for their futures</li> <li>• Couples' testing is viewed as protective to a relationship's future</li> </ul>	<ul style="list-style-type: none"> <li>• Getting tested for HIV is considered a moment of truth in relationships – the results allow a couple to either take their relationship to the next level or end it</li> </ul>
<b>ii. Communication</b>	<ul style="list-style-type: none"> <li>• Frank communication with community members about HIV testing is important to relieve personal and inter-personal stress related to HIV</li> <li>• Being open about getting tested for HIV with a partner respects both partners' stakes in the relationship</li> </ul>	<ul style="list-style-type: none"> <li>• Frank communication with partners about HIV testing is important to relieve personal and inter-personal stress related to HIV</li> </ul>	
<b>iii. Delayed Testing and Forced Testing</b>	<ul style="list-style-type: none"> <li>• Delaying testing following initial symptoms of HIV is harmful to one's physical and social wellbeing</li> <li>• Avoiding getting tested ultimately leads to a loss of independence and privacy</li> <li>• It is possible that HIV-related stigma and discrimination are perpetuated by the practice of delaying testing</li> </ul>	<ul style="list-style-type: none"> <li>• Delaying testing is delaying treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Delaying testing is delaying condom use</li> <li>• Forced testing by employers often leads to being fired if one tests positive</li> </ul>

	because people experience visible symptoms of HIV in the public eye, generating fear within communities		
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**Table 1E: Summary of Male Involvement and Participation in SRH (ART and ARVs)**

	<b>He Said</b>	<b>They Both Said</b>	<b>She Said</b>
<b>i. ART &amp; ARV Interactions</b>	<ul style="list-style-type: none"> <li>• ART does not reduce condom use</li> <li>• There is concern about a shortage of companion drugs for ARVs</li> </ul>	<ul style="list-style-type: none"> <li>• The use of ARVs alone is not sufficient to prevent mother-to-child transmission of HIV (needs to be supplemented with condom use and additional drugs from the hospital)</li> </ul>	<ul style="list-style-type: none"> <li>• It is possible that ART reduces condom use</li> </ul>
<b>ii. Use of ART While in a Relationship</b>	<ul style="list-style-type: none"> <li>• Undergoing ART without one partner's knowledge is problematic</li> <li>• Sometimes when both partners are on ART, some men become unfaithful</li> </ul>		<ul style="list-style-type: none"> <li>• Men refuse to use condoms when both partners are on ART</li> </ul>
<b>iii. ART Acceptability</b>	<ul style="list-style-type: none"> <li>• ARVs are a visible symbol of living with HIV, which may often be used against PLWHIV by peers who stigmatize and discriminate, but the physical and mental clean slate that it affords people is worth the reminder</li> <li>• ARV users have the upper hand when being laughed at by their peers because their health is being restored while their teasers' health is at risk</li> <li>• ART may or may not impact libido</li> <li>• Leg and back pain are often side effects of ARVs</li> </ul>	<ul style="list-style-type: none"> <li>• ART is life-giving</li> </ul>	<ul style="list-style-type: none"> <li>• Being dependent on drugs for a lifetime is undesirable</li> <li>• Irregular menstruation is often a side effect of ARVs</li> <li>• Physical appearance is often changed by taking ARVs; this is perceived as a negative side effect</li> </ul>

## Chapter 5: Discussion and Recommendations

### 5.1 Summary of Findings

The goal of this analysis was to understand how heterosexual men and women living with HIV in Lilongwe, Malawi, perceive men's roles in SRH, particularly in the prevention of vertical transmission of HIV. In addition to assessing men and women's beliefs about men's roles in family planning, VCT, and antenatal care, the central questions also explored how gender norms affect attitudes about male involvement and participation in SRH.

The key finding in this study is that men and women experience multiple competing realities when navigating sexual and reproductive health issues. Male and female perspectives on male involvement in SRH often differed and even opposed one another. Disagreement between men and women was pervasive about perceptions of HIV risk and vulnerability, expectations of childbearing and condom use, the meaning of protection, contraceptive decision-making, and communicating both intentions to get tested and test results. Placing emphasis on how men differ from women without also considering variation among men themselves would be negligent considering that differences in SRH attitudes *among* men may be greater than differences *between* men and women (Greene & Biddlecom, 2000). This study found disagreement among men regarding partner refusal of condoms, the evolution of family planning, men's roles in family planning, and abortion. Because of the effects that these discrepancies could have on pediatric HIV outcomes (and

more broadly, on other aspects of maternal and child health and HIV prevention), understanding variation in knowledge, attitudes, and behavior of men and women living with HIV on men's roles in SRH could have wider implications for male involvement.

## **5.2 He Said, She Said**

### ***Condoms***

This study found that men and women's perception of HIV risk and vulnerability differed. Men believed that only unmarried women are at risk of contracting HIV because of the perception that HIV is associated with promiscuity and the assumption and expectation that married women are monogamous. Women, however, believed that everyone, including married women, is at risk of contracting HIV given that husbands often engage in extramarital sex (and wives sometimes do as well). This study's data contradicts the cultural assumption that men are promiscuous and women are faithful, as some women engaged in extramarital sex. Cultural assumptions directly influenced attitudes about women carrying condoms in public, which men deemed appropriate for unmarried women only. Women, however, believed everyone should carry condoms in public to protect themselves, their families, and their communities. Another study in Malawi found that married women report worrying most about their husbands as a possible source of infection, while married men report worrying most about their extramarital partners (Smith & Watkins, 2005). These findings are consistent with this study's findings and have implications for HIV risk behavior. For example, a study in Kenya that used logistic regression models to examine the direction and

strength of the association between perceived risk of HIV and risky sexual behavior in the previous 12 months revealed a strong positive association between perceived risk of HIV and previous risky sexual behavior for both men and women (Akwara, Madise, & Hinde, 2003). If men do not perceive married women to be at risk of contracting HIV, they may not use condoms when having sex with their wives. Such misperceptions have implications for HIV testing, since men and women living with HIV who do not perceive themselves to be at risk of contracting HIV may delay or forego HIV testing. Further, knowing both partners' HIV statuses is crucial to preventing MTCT. Education programs should be used to dispel myths about HIV and provide facts about contextually relevant HIV risks.

In the present study, men characterized themselves as committed to the public health goals of preventing vertical and horizontal transmission of HIV. Women, however, observed that despite men's awareness of the public health community's expectations of avoiding pregnancy and practicing regular [male] condom use while living with HIV, men often prioritized society's expectations of bearing children and engaging in unprotected sex within marriage. These findings are consistent with the literature, which indicates that in Malawi, only one-quarter of sexually active individuals report having used a condom (Bisika, 2008). Bisika explains these low levels of condom use as associated with cultural practices, such as extramarital sex and religious beliefs (i.e., "be fruitful and multiply"), which compete with public health practices (condom use and the avoidance of pregnancy). Of particular concern is the finding that many people believe there are more

barriers to avoiding HIV and using condoms than simply changing attitudes, suggestive of the notion that cultural factors have a stronger influence on behavior than on attitudes (Bisika, 2008). One such barrier to using condoms is male partner refusal, which can lead to female partner refusal to have sex, which can subsequently lead to quarrels and withholding of economic support or divorce. If acceptability of condoms is low among men living with HIV in Lilongwe and women are unable to negotiate their use, then PMTCT providers promoting condom use at ART clinics and antenatal care facilities may be wasting time and resources. Mass media educational campaigns should work to change cultural attitudes about extramarital sex and fertility. Alternatively, public health efforts could be directed toward researching the acceptability of female condoms or vaginal microbicides.

Another example of the dissonance in perceptions between genders was that men expressed that sex without a condom symbolizes a deeper trust and commitment to one's partner, while women believed that unprotected sex is threatening to their health and lives. This study's findings about men's attitudes toward condoms were consistent with a mixed-methods study conducted among women at a methadone clinic in New York City (Pivnick, 1993). The New York study found that patients at the clinic viewed non-condom use as confirmation of a partner's intimacy and fidelity. For the New York population, the non-use of condoms was perceived as the purest and most intimate way to express conjugal bonding (Pivnick, 1993). Clearly, the New York and Lilongwe study populations differed in meaningful ways. Although these study populations are not comparable,

the fact that they presented with the same finding could facilitate future context-specific research on meanings ascribed to condoms. As this study's findings about the meaning of "protection" (and "non-protection") reveal, meanings ascribed to condoms in Lilongwe may directly compete with Lighthouse Trust clinic providers' methods for preventing vertical and horizontal transmission of HIV. Future research should explore context-specific meanings ascribed to condoms.

### ***Contraception***

This study found that men presented themselves as authority figures within sexual partnerships responsible for autocratic (individual), consultative (involved), and collaborative (shared) decision-making regarding fertility behavior and consequently couples' uptake of family planning. Women presented men as primarily autocratic and sometimes consultative decision-makers about childbearing matters, suggesting that men either make decisions independently or involve their partners, but ultimately make final decisions themselves. Shared decision-making did not seem to be a reality for women. Thanks to a growing body of evidence that men's and women's fertility desires often differ, researchers have explored questions around the comparative influence of each partner's fertility preferences relative to the other. This study's findings are consistent with those of a study in Kenya, which found that contraceptive uptake was two to three times more likely when husbands rather than wives desired to stop childbearing (Blanc, 2001). Another study in Nigeria found that the husband's desire for additional children dominated when the number of living children was small, but that the effect of the wife's desire became greater as the number of living children increased (Blanc,

2001). Future research should explore whether HIV modifies this effect. Family planning interventions could target partners by gender based on a couple's number of existing children. Because preventing HIV-positive pregnancy is one of the four components of comprehensive PMTCT programs, the ability to control pregnancy is critical for preventing pediatric HIV infections.

Most women addressed their lack of control over open fertility decision-making within sexual partnerships by practicing surreptitious fertility decision-making (i.e., covertly practicing family planning with non-visible methods such as intra-uterine devices). Women were able to access family planning in secret thanks to the integration of antenatal care and family planning programs; they either pretended to take their existing children for antenatal services or sought contraception during their children's actual appointments. However, women expressed concern that they learned about family planning too late (i.e., after getting pregnant and presenting to the antenatal clinic) because there were no spaces for family planning education for childless couples. The practice of covert female-controlled contraception use is well documented in the literature. One study in Zambia found that women's covert use of contraception may account for 6 to 20% of all contraceptive use and that the practice is more widespread when contraceptive prevalence is low (Biddlecom & Fapohunda, 1998). These findings should be taken into account when designing family planning interventions. The integration of antenatal care and family planning services should be considered at the Lighthouse Trust clinics (one clinic is already integrated). Family planning education programs

that capture childless couples are needed. These could be widely advertised on the radio, given the approval of radio-delivered public health messages by this study's participants.

### ***Voluntary HIV Counseling and Testing***

This study's data indicates that men viewed open communication between partners, community members, and co-workers about both intentions to get tested and test results as positive and relieving of inter- and intra-personal stress. Women sometimes viewed open communication between partners this way, but often felt that it exacerbates stress, especially in distrustful relationships and at the office. While men reported no change in employment status over disclosing a positive HIV status at the office, women reported being dismissed from their jobs. Additionally, women feared disclosing a positive HIV status to their partner because they expected consequent marital stress or divorce. Fear as a barrier to disclosing one's HIV status is prevalent in the literature, particularly among women. This study's data complements another study's findings. Data collected in Atlanta, Georgia, on patterns of HIV status disclosure and social support indicate that perceived stress of disclosing HIV status is associated with disclosure and social support (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). Fear of HIV status disclosure has major implications for PMTCT. One of the four components of comprehensive PMTCT programs is preventing HIV-positive pregnancies. Women who feared disclosing their HIV status to the community (and thus kept it a secret) were faced with significant peer pressure from extended family and friends to get pregnant. They were forced to decide between navigating stigma and discrimination from

community members that follows disclosure of a positive status and navigating an HIV-positive pregnancy (given their male partner's approval). Interventions are needed that focus on community education, couples' counseling, and the mitigation of HIV stigma and discrimination.

### **5.3 Variation Among Men**

This research suggests that disagreement among men living with HIV on SRH issues is also prevalent in Lilongwe.

#### ***Partner Refusal of Condoms***

While most men acknowledged their frustrations with condoms, few acknowledged refusing to use them. One man, however, blamed men for their negligence and selfishness regarding condom refusal and directly attributed unwanted pregnancy to this behavior. Alternatively, another man blamed women for "playing tricks" on men to avoid using condoms. Others thought women lacked power to negotiate condom use. The fact that some participants have thought critically about gender norms and power dynamics and their impact on condom use is a positive indication that the process of awareness raising about such norms and dynamics is underway. However, these conflicting beliefs may warrant further research on the interaction of gender norms with condom use in Lilongwe. Additionally, emphasis should be placed on interventions that encourage the break down of gender inequality.

### ***The Evolution of Family Planning***

Men expressed three distinct theories about the widespread use of modern family planning methods in Malawi:

- 1) Agricultural challenges compete with couples' fertility desires. Land and food security are major problems in both rural and urban Malawi. Fewer mouths can be fed. Fewer mouths can be born.
- 2) "White men" are modifying traditional African contraceptive methods and selling them back to Africans for a profit. Technology is taking over Malawi. Malawi is buying it.
- 3) Cultural norms around the age at first marriage are shifting. Men and women are getting married earlier and thus spend more of their reproductive lifecycle together. To adjust, couples need better control over birth spacing.

The fact that men presented intersectional information about family planning in a "cause and effect" framework deserves attention. Food security, Western technology, and decreasing age at first marriage were identified as "causes" and family planning use as "effect". Public health practitioners working in development could be useful allies in helping to address barriers to and facilitators of family planning use.

### ***Men's Role in Family Planning***

While most men believed husbands were responsible for advising wives on family planning issues, some men expressed disagreement. Several men felt uneducated about family planning and did not feel welcome in spaces that formally shared information about contraception. Others considered family planning women's business. One man believed that women's responsibility of childbearing should come with the privilege of managing that process; he believed women have the right to choose their own contraceptive methods and male partners should simply provide support. Although this man's opinion was unique among the male participants, it is suggestive of the idea mentioned above that gender reconstruction in Lilongwe may already be in progress. The literature recommends reaching out to men about family planning issues via mass media (Piotrow et al., 1992). Another potential strategy is to provide family planning education and services at non-health (male-friendly) facilities such as churches or bars. This approach has been found to be more effective than health care facilities in attracting male participation in couples' HIV testing and counseling (Sherr & Croome, 2012). The bottom line is, if men are in control of family planning decision-making, they need to have the skills to make informed, evidence-based decisions. This is especially relevant for men and women living with HIV who risk not only the female partner's health, but also their child's health by having an HIV-positive pregnancy.

### ***Undesired Pregnancy and Abortion***

Men presented conflicting ideas about the availability of safe abortions in Malawi. Most men expressed that women do not have the option of terminating unwanted pregnancies. However, others disagreed and even cited the name of an abortion provider (BLM). There was also disagreement about which partner controls decision-making about abortion, with most men believing that the male partner individually makes that decision and others believing the opposite. According to the Malawi Ministry of Health, although abortion is officially illegal in Malawi, it is regularly practiced with 70,000 Malawian women having abortions every year. In practice, authorization must be obtained by two different obstetricians and also by male partners. Unsafe abortion is one of the leading causes of maternal mortality in Malawi and causes 30% of all admissions in gynecological wards (Jackson, Johnson, Gebreselassie, Kangaude, & Mhango, 2011). One possible strategy for addressing male control over abortion decision-making is using gender-sensitive education and awareness raising about the realities and consequences of unsafe abortions. Reforming both official and unofficial abortion policy could have a wider impact on preventing unsafe abortions.

### **5.4 Recommendations for Lighthouse Trust**

It is widely understood that gender is a social determinant of health (Larsson et al., 2010). A growing body of evidence from both developed and developing countries consistently suggests that women who experience gender inequality are at greater risk of HIV (Dunkle & Jewkes, 2007). Looking to the literature, a study in Boston found that young men (aged 18-35 years) attending an urban community

health center were more likely to report recent unprotected vaginal sex within their heterosexual relationships if they prescribed to the more traditional masculine gender role ideologies (Raj, Decker, La Marche, & Silverman, 2006). Given that male sexual risk taking is reinforced by social ideas of masculinity, gender roles and norms are influential factors of male involvement in PMTCT and in the wider field of SRH among PLWHIV in Lilongwe, Malawi. Gender inequality is a barrier to improving health outcomes in all four components of comprehensive PMTCT programs – preventing HIV in women and girls, preventing unintended pregnancies among women living with HIV, preventing HIV transmission from mothers to their infants, and providing care to women living with HIV and their families (Ghanotakis, Peacock, & Wilcher, 2012). Providers at the Lighthouse Trust clinics exploring potential solutions to public health problems (i.e., vertical and horizontal transmission of HIV, infant and maternal mortality, high fertility rates, ART non-adherence, etc.) affecting their patients must address gender roles and norms as an integral feature of their SRH programs.

This study's qualitative findings are valuable for establishing normative context with respect to gender and power. Men were found to dominate decision-making around childbearing and condom use. Additionally, women's financial dependence on men limited their access to and use of SRH services. Women's ability to: (1) acquire information; (2) decide; (3) and act within SRH domains (e.g., fertility regulation, pregnancy support and delivery, and abortion care) was often controlled by men. A potential first step for Lighthouse Trust providers would be to collect

explicit data on gender dynamics within Lilongwe's HIV-positive community. This research could be used to develop contextually appropriate SRH interventions.

Gender hierarchy is an undervalued challenge in PMTCT programs, which often expect women to disclose their positive HIV statuses to their partners, share knowledge acquired at antenatal clinics, and request that their partners be tested for HIV (Falnes et al., 2011). These behaviors may be perceived as unacceptable within some social and cultural contexts, such as patriarchal countries like Malawi. Context-specific strategies that limit the barriers and enhance the facilitators to male partner involvement should be utilized at multiple levels because power in sexual relationships is resultant from multilevel processes (Morfaw et al., 2013). Refer to Appendix 1 for a full list of evidence-based barriers and facilitators to male involvement and participation in PMTCT.

For men and women living with HIV in Lilongwe, societal and cultural barriers to MIP may be particularly relevant intervention targets. The stereotype of antenatal care being "women's business" needs to begin to be broken down. Improving "acceptability" is one of the "5 A's" of antenatal service venues (along with accessibility, affordability, availability, and accommodation) that will lead to increased male involvement and participation in PMTCT (John Ditekemena et al., 2012). Another possible strategy for Lighthouse providers is to unlink PMCTC services from maternal and child health units, which in their current form are perceived by men to jeopardize their masculinity (Chinkonde, Sundby, & Martinson,

2009). Cultural patterns of gender norms around communication require further investigation. The stakes are higher for women to disclose their positive HIV statuses, given that HIV is still highly stigmatized in Malawi as being associated with promiscuity (and promiscuity is only punishable in women). Men perceive wives' infidelity as grounds for divorce. Marital breakdown is not only perceived as shameful for women, often leading to an indefinite state of widowhood for those living with HIV, but also cuts off financial resources that they depend on for survival (Chinkonde et al., 2009). Therefore, women often fear disclosing their status to their partners and thus cannot even broach the topic of condom use. Continuous community education campaigns to demystify HIV and mitigate stigma should be used to change negative attitudes about living with HIV, reduce fear of disclosing one's status, and facilitate open communication between partners and among community members (Chinkonde et al., 2009).

Globally, interventions aimed at addressing power relations have been found to be both feasible and acceptable to program implementers and clients. However, more context-specific data is needed to build the evidence base describing feasibility and acceptability under different circumstances. Interventions that address the balance of power within sexual relationships must incorporate measures of power relations in their evaluation strategies to elucidate the effects of power relations on sexual and reproductive health outcomes (Blanc, 2001). Strategies such as small-group educational workshops about gender norms may be

feasibly and cost-effectively integrated into existing programs at the Lighthouse Trust clinics.

In conclusion, interventions that protect both men's and women's sexual and reproductive health necessitate active transformation of underlying gender norms that legitimate male power, male control, male violence, and men's sexual risk taking (Dunkle & Jewkes, 2007). Ultimately, developing programs that incorporate the different beliefs, attitudes, and behaviors of men and women, balance the knowledge that men often control decision-making within sexual partnerships with the rights of women to control their own reproductive health behaviors, and work to break down harmful gender norms may effectively improve MIP in SRH and subsequently reduce pediatric HIV infections. Additionally, there may be positive spillover effects in other areas of maternal and child health and HIV prevention.

### **5.5 Strengths and Limitations**

The major strength of this study was its engagement of both men and women. Because focus group data on men about SRH is scarce in the literature, this framework is novel. Additionally, secondary data is important for generating hypotheses to be studied in future research.

One important limitation of qualitative research is the fact that findings are not always generalizable to a broader population. Therefore, this research may be context-specific to men and women living with HIV attending ART clinics in Lilongwe. Additionally, observation was not a component of this research, so it is

possible that what men and women said they do and what they actually do may differ. Finally, a potential weakness of this study was the fact that it did not collect couple-level data, so issues expressed by men and women about their partners could not be compared to issues expressed by their partner.

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## Appendix 1

**Table 2: Summary of barriers and facilitators to MIP in PMTCT**

<b>Table 2.A Summary of barriers to MIP in PMTCT</b>	<b>Table 2.B Summary of facilitators to MIP in PMTCT</b>
<p><b>Societal/cultural barriers</b></p> <ul style="list-style-type: none"> <li>• Perception of antenatal care as a woman's place</li> <li>• Cultural norm that men should not participate in antenatal care as pregnancy is a woman's affair</li> <li>• Societal ridicule of men accompanying their wives to ANC</li> <li>• Women are not allowed to lead</li> <li>• Conflict between PMTCT recommendations and cultural norms such as breastfeeding</li> <li>• Cultural patterns of communication</li> </ul> <p><b>Male individual factors</b></p> <ul style="list-style-type: none"> <li>• Reluctance to learn one's status</li> <li>• Lack of time for ANC/PMTCT</li> <li>• Do not see the benefits of testing</li> <li>• Self-perception of being in good health</li> <li>• Avoidance of the burden of care</li> <li>• Lack of finances</li> <li>• No one left at home to look after the children</li> </ul> <p><b>Information/knowledge barriers</b></p> <ul style="list-style-type: none"> <li>• Misconception that your partner's HIV status is a proxy of your own status</li> <li>• Unawareness of the availability of antenatal VCT by men</li> <li>• Men's limited knowledge of PMTCT</li> <li>• Lack of community awareness on the importance of male PMTCT involvement</li> </ul> <p><b>Health system barriers</b></p> <ul style="list-style-type: none"> <li>• Long wait times at the clinic</li> <li>• ANC services are not male-friendly</li> <li>• Distrust in confidentiality of the health system</li> </ul> <p><b>Female individual factors</b></p> <ul style="list-style-type: none"> <li>• Women not involving their partners due to numerous fears, e.g. accusations of infidelity, divorce, stigmatization, domestic violence</li> </ul> <p><b>Relationship dynamics factors</b></p> <ul style="list-style-type: none"> <li>• Weaker relationships</li> </ul>	<p><b>Health system facilitators</b></p> <ul style="list-style-type: none"> <li>• Invitation letters from health services inviting men to PMTCT</li> <li>• Offering routine voluntary couple counseling</li> <li>• Provision of counseling services during non-working hours</li> <li>• Offering of counseling and testing for HIV at sites other than antenatal care</li> <li>• Availability of health personnel to encourage testing and facilitate disclosure</li> <li>• Change from voluntary counseling and testing to routine counseling and testing</li> <li>• Offering of counseling and testing for HIV within antenatal settings</li> <li>• Differential targeting and offering of counseling and testing of HIV to men accompanying their wives to the delivery wards</li> <li>• Holding of open discussions on free antenatal HIV testing for partners</li> <li>• Differential counseling for HIV positive women</li> <li>• Community sensitization activities</li> <li>• Availability of anti-retroviral drugs in the health center</li> </ul> <p><b>Relationship dynamics factors</b></p> <ul style="list-style-type: none"> <li>• Monogamous marriage or cohabitation of partners</li> <li>• Discussion of PMTCT within the couple</li> <li>• Sero-concordance for HIV</li> </ul> <p><b>Male individual factors</b></p> <ul style="list-style-type: none"> <li>• Previous male testing for HIV</li> <li>• Providing men with time to consider PMTCT recommendations</li> <li>• Increased male knowledge concerning HIV and perceived benefits of PMTCT</li> </ul> <p><b>Female individual factors</b></p> <ul style="list-style-type: none"> <li>• Lack of financial dependence on the part of the woman</li> <li>• Positive attitudes of women towards disclosure of their test results</li> </ul>

<ul style="list-style-type: none"> <li>• Fidelity within the relationship</li> </ul> <p><b>Disagreement with PMTCT teachings</b></p> <ul style="list-style-type: none"> <li>• Disagreement with PMCTC encouragement of condom use within the couple</li> <li>• Men perceiving antenatal VCT as a late event; they would have been offered the chance to test earlier</li> </ul>	
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**ANC = Antenatal care, PMTCT = Prevention of mother-to-child transmission, VCT = Voluntary counseling and testing, HIV = Human Immuno-deficiency Virus**

**\*\*Tables replicated from Morfaw *et al. Systematic Reviews* 2013**

## Appendix 2

### **Focus Group Discussion Guide (English)**

#### Introductory Statement:

Thank you all for coming today to this meeting. My name is \_\_\_\_\_. My team and I are talking with groups of people about sexual and reproductive health for people with HIV here in Malawi. When talking to groups, we will address pregnancy desire, family planning and sexual practices. Our research team is going to talk to several groups of women or men who receive care at the Lighthouse clinic or Martin Preuss Clinic about what they know and are interested in relating to family planning, their pregnancy desires, their sexual practices and other issues related to their reproductive and sexual health. We want to do this research because we feel it is important to hear the views of women and men in order to eventually create a program that meets your needs. We will be asking questions about desire for children, use of family planning, attitudes and knowledge of different family planning methods, relationships and your home lives, sexual practices and how having HIV may have influenced some of these issues. We will also be asking about how antiretroviral therapy may affect some of these issues. All of your voices are very valuable to us and it is important to tell you that there are no right or wrong answers, so please share your opinions and experiences with us without feeling shy. Please feel comfortable telling us what you really think!

Your participation in this group is completely voluntary. You will be participating in the group with other individuals who are also HIV positive. Whatever is said here today is completely confidential and will be used only our research purposes. Please do not share anything we talk about in the group with people outside of the group, even if that person is going to be in another focus group. During the discussion \_\_\_\_\_ will be taking notes, \_\_\_\_\_ will be asking the questions. We will also be tape recording the discussion, so that if we missed some things in the note taking, we can listen to the discussion again and make sure we understood exactly what was said by you. We will use only nicknames or numbers in the discussion, and there will not be any information on here that could identify you, and therefore your confidentiality will be maintained.

When we ask questions, please join in whenever you have something to say. We will not be going in any order. However, please take turns speaking so we don't miss any of your important opinions and experiences. Remember that this is a discussion, not a test, so there are no right or wrong answers. If you have other opinions than what others have said, please share your beliefs. We want to hear as many different points as possible, so again feel to share your own opinions. But please remember to be respectful of each other. This discussion will probably last about two hours. We will be taking a short break after one hour of discussion for snacks. If at anytime during the course of the discussion you want to leave or go to the bathroom, \_\_\_\_\_ can help you. Are there any questions before we begin?

### Introductory Questions:

Let's go around the room and introduce ourselves using nicknames or numbers only, and then we would like to know what you think are the most important health problems for women and men in Malawi today.

### Main Body Questions:

1) What methods of family planning have you heard of women or men using? Which methods tend to work best? Are certain methods better for those with HIV or those on ART?

2) I would like us to think about the services that are available in or near this community for a person to access family planning. Where can women get family planning methods and how are they paid for? Where do men and women learn about Family Planning/preventing pregnancy? (school, mother, grandmother, friends, doctors or other health care providers, the market place, after having a baby, they don't?) [location and content of messages- what are they and are they same for those who have HIV and those who receive ART]

- What kind of services are there?
- How many services are there? (Do you feel these are good services?)
- What do people like or dislike about these services? Are there any ways in which these services could be improved?)
- How is it different for those with HIV or those who receive ART? is there more pressure or less pressure to use these methods
- Do providers offer men and women with HIV the same options for contraception?

3) In general, what is the ideal family size in Malawi and why is this so?

- How does a partner or spouse play a role?
- What is the best amount of time between children?
- how many children do most women want in Malawi, is this different for men?
- Do people feel differently about how many children they should have if they are diagnosed with HIV?
- What if the man has HIV and not the woman? What if the woman is HIV and not the man?
- Do people in the community think differently about how many children someone with HIV should have?

4) Now thinking about the number of children you have or the number that you may want, if any, can you tell me how you came to this number?

- Is it important in Malawi to have boys or girls? Why?
- How usually do people decide on the number of children they have
  - Who usually makes the decision the have children?
  - Is there a time or place where couples discuss these issues?

- Is it common for women to get pregnancy when they do not want children?
  - Is it more common for the woman or men to want more children? (Did you want fewer children but got pregnant or did your spouse want more children?)
  - Does anyone else influence this decision? (How do friends, family or other people in the community take part in this decision?)
  - Does HIV influence the number of children people want or people have
  - Does ART influence the number of children people want or people have
- 5) How do people in your community feel about family planning/taking measures to prevent pregnancy?
- Are people in the community supportive or not supportive of family planning use? (Why do you think? Do women and men feel differently about family planning use?)
  - Would someone feel differently about using family planning if they were HIV+ (have your feelings changed since being diagnosed with HIV?)
  - What about condoms? What do people in the community feel about condoms use? Is it the same for female and male condoms? Are people supportive of using a second method in addition to a condom to help prevent pregnancy
- 7) In general, what things influence a man or woman's decision to use family planning/prevent pregnancy? (price, religion, easy access to clinic, mother or partner's opinion, # of pregnancies, # of living children, economic difficulties, fear of side-effects)
- Do women/men have any fears or worries about using family planning? (prompt – side effects you have had or heard of from other women, future infertility, what have you heard or witnessed that are problems with family planning methods?).
  - Are these concerns different for individuals with HIV?
  - Does this change for people who are taking ART.
- 6) If there was a perfect family planning method for you, what features would it have? Prompt: no hormones, long lasting, inexpensive.
- What opinions have you heard about Depo Provera? The LOOP? Norplant? The Pill? Male Condoms? Female Condoms?
  - Have you ever heard of anyone using Emergency Contraception? What were the circumstances and what was the outcome? Where did she/he get it?)
  - What about people using 2 methods together, such as condoms and Depo provera? Why would they go for this?
- 8) I want to think more about how people in your community view having children. Is it ok for a school girl to get pregnant? What if she was not in school? Would people feel different if she was married? not married?
- Would people feel different if she was older? What is a good age to start having children?
  - How many children should a woman have? Are too many children looked down upon?

- How would people feel if she had HIV?
- How would people feel if she was taking ART?
- What about if her partner had HIV and she did not? Is it different if she is HIV positive as well?

9) What about use of family planning. Let us think about a situation in which a young girl or young boy wants to use a method of birth control. How do people in the community feel about that?

- Does it matter if she has had child?
- Would it make you feel different if she had HIV?
- How would people feel if she was taking ART?
- What about if her partner had HIV? And she did not? Is it different if she is HIV positive as well.
- Would you be ok with to use any method of birth control or are only certain methods ok

BREAK:

Welcome back. Let us go back to where we left off. We were discussing pregnancy intentions and family planning use. Now I want to shift to discuss a bit more specifically about condom use

9) During sexual encounters, in general who decides whether a condom is used? (both partners, the man, woman)

- In what situation would a woman have the right to make a man use a condom
- In what situation would a man have the right to make a woman use a condom
- How acceptable is it for a woman to carry the condom and suggest her partner use the condom, is it different for a female condom or a male condom
- How acceptable is it for a man to carry the condom, is it different for a female condom or a male condom
- If the woman was single, would people feel different?
- If they THINK partner is promiscuous?
- If they KNOW partner is promiscuous?
- What would people think if she was HIV+?
- What would it be different if her partner was HIV+?

10) If someone is using a method of contraception, such as an LOOP or Depo or Norplant, would that influence their choice to use a condom during intercourse? Is it different for those with HIV or those on ART? Is it different if they are in a monogamous or married relationship?

11) How might sexual behavior change for someone who is HIV+ (use of a condom, abstinence?, do some people have less pleasure from intercourse)

- How does this differ based on their partner's HIV status?

- What changes would there be for those who are using antiretroviral therapy (does antiretroviral therapy reduce condom use?)
- What are some other concerns related to sexual health that might be different for someone with HIV?

12) Finally I want to open up the discussion to address other concerns or issues related to reproductive health that might be influenced by having HIV.

- Does HIV cause other issues that are related to your reproductive health (irregular bleeding, infertility, menopause, pelvic pain, cancer, libido changes?)
- What services are available to address these needs related to reproductive health?
- What do you like or dislike about the services
- What are the ways these services could be improved?

13) I want to understand some of your views on the medications people are taking for HIV (ART) and how it may impact reproductive health, sexual behavior and fertility

- Is it safe to have a pregnancy
- Do you have more/less sex when on it
- Are different regimens different or do they have different effects on these issues?
- Does it effect the ability to transmit HIV to your baby
- Does it effect your ability to transmit HIV to your partner
- Does it effect your decision to use a condom

Conclusion:

We are getting towards the end of our discussion. Does anyone have any other comments to add to what we have been talking about before we conclude? Thank you all very much for coming. We appreciate your contribution to this research project and we hope that the experiences you have shared will help women and men in the future with their reproductive health needs.

**Please collect:**

**AGE, MARITAL STATUS, # of CHILDREN, OCCUPATION AND LENGTH OF TIME SINCE STARTING ART**

### **Focus Group Discussion Guide (Chichewa)**

Malonje: Zikomo nonse pobwera lero ku msonkhano umenewu. Dzina langa ndine \_\_\_\_\_. Gulu langa ndi ine tikulankhula ndi magulu a wanthu okhudza uchembere wa anthuchilakolako cha kukhala ndi mimba, kulera ndi muchitidwe ogonana. Gulu lanthu la anthu akafukufuku adzalankhula kwa magulu angapo a amai kapena a abambo amene amalandira thandizo ku kiliniki ya Light House kapena kiliniki ya Martin Preuss zokhudza zimene amadziwa ndi zimene ali nazo chidwi zokhudza kulera, chilakolako chokhala ndi mimba, muchitidwe wawo ogonana ndi zina zokhudza uchembere. Tikufuna kupanga kafukufukuyu chifukwa tikuona kuti ndizofunika kumva maganizo a amai ndi a bambo kuti kenaka tikonze pologalamu / ndondomeko zomwe zingakwaniritse zofuna zanu. Tidzifunsa mafunso okhudza chilakolako chokhala ndi ana, kugwiritsa ntchito maleredwe, zikhalidwe ndi kudziwa za njira zosiyanasiyana za maleredwe, zibwenzi ndi moyo wanu wa pakhomo, muchitidwe ogonana ndipo mmene kukhala ndi HIV kwakhudzira zinthu zinazi. Tidzifunsanso zokhudza mmene ma ARV amakhudzira zinthuzi. Zonse munene ndizofunikira kwambiri kwa ife ndipo ndikofunika kukuuzani palibe mayankho okhoza kapena olakwa, ndiye chonde gawanani maganizo anu ndi zokumana nazo ndi ife popanda kuchita manyazi. Chonde khalani omasuka kuti zina zimene mukuganiza!

Kutenga nawo mbali kwanu mu gulu ili nkoziperereka nokha. Zimene zilankhulidwe pano lero ndi zachinsinsi kotheratu ndipo zidzgwiritsidwa za kafukufuku zokha basi. Chonde osagawana chiri chonse tilankhule mu gulu ndi anthu kunja kwa gulu, ngakhala kuti munthu winayo akhale mu gulu lina la zokambirana. Munthawi yokambirana \_\_\_\_\_ azilemba, \_\_\_\_\_ azifunsa mafunso. Toidzijambulanso kukambiranaku, kuti ngati talumphu zinthu zina mukulemba, titha kumvetseranso muzokambirana ndi uonetsetsa zenizeni zinakambidwa ndi inu. Tidzagwiritsa ntchito maina opeka okha muzokambirana, ndipo sipakhala uthenga pano okuzindikiritsani inu, ndipo chonco chinsinsi chanu chidzasamalidwa. Tikafunsa mafunso, chonde gweramoni pamene muli ndi china choti mulankhule. Sitizitasa ndondomeko ili yonse. Komabe, patsanani mpata kulankhula kuti tisasowe chonse chofunikira cha mfundo zanu ndi zokomana nazo. Kumbukirani kuti uku ndi kukambirana, osati mayeso, tsono kaya simukugwirizana ndi wina, chonde nenani. Tikufuna kumva mfundo zosiyanasiyana zochuluka mmene tingathere, tsono ndibwereze masukani kusagwirizana ndi wina ndipo gawanani mfundo zanu. Koma chonde kumbukirani kulemekezana wina ndi mzake. Kukambiranaku kudatenga mwina maola awiri kufikira a tatu. Tidzapuma pang'ono pakatha ola limodzi la kukambirana kudya tonyong'onoyera mkamwa. Ngati kanthawi kena mkati mwa zokambirana mukufuna kuchoka kapena kukazithandiza ku lu,, \_\_\_\_\_ atha kukuthandizani. Pali mafunso ali onse tisanayambe?

Mafunso kuchokera mumalonje:

Tiyende mozungulira meu chipinda ndi kuzilongosola tonse pogwiritsa ntchito maina ongopeka okha, ndipo kenaka chonde tiuzeni zaka zanu ndi kuchuluka kwa

ana muli nawo. Tifunanso kudziwa zimene mukuganiza ndi ziti zovuta kwambiri kwa miyoyo ya amai ndi abambo mu Malawi lero/ panopa.

Mafunso mudzokambirana:

1) Tsopano kuganizira kuchulika kwa an mili nawo, mungandiuze mmene munaganizira kukhalala ndi ana ambiri onsewo?. Kodi ndizofunikira m Malawi kukhala ndi ana amuna kapena akazi? Chifukwa?

- Kodi ndani amapanga ganizo lokhala ndi ana? Kodi nchapafupi kwa mkazi kukhala ndi mimba asakufuna ana Kodi nchapafupi kwambiri kwa mai kapena abambo akunyumba kufuna ana ambiri? Kodi inu munapanga chiganizo? Kodi munafuna ana ochepa koma nkutenga mimba kapena abambo akwanu anafuna ana ambiri?
- Kodi amai amapanga bwanji chiganizo chokhala ndi ana ndi abambo akwawo?
- Kodi wina amalimbikitsa chiganizo chimenechi?
- Kodi a bwenzi, abanja ndi anthu ena mu dera amatengapo mbali bwanji pa chiganizochi?
- Kwa amai amene ali ndi HIV kapena ali pa ma ARV , kodi moyo wawo ndi mankhwala amakhudza bwanji chiganizo chawo chokhala ndi mwana?

2)Mwa zonse, kodi mulingo weniweni wa kuchuluka kwa ana ndi uti mMalawi ndipo ndi chifukwa chiani izi zili chonchi?

- Kodi okonedwa kapena akunyumba amatengapo mbali bwanji?
- Kodi ndi kutalikirana bwanji pakati pa ana kumene kuli kwabwino?
- Ndi ana angati amene amai ambiri m Malawi amafuna, kodi izi zikusiyana ndi abambo?
- Kodi anthu amamva mosiyana zokhudza kuchuluka kwa ana angakhale nawo ngati apezeka ndi HIV?
- Nanga ngati abambo ali ndi HIV osati amai? Nanga ngati amai ali ndi HIV osati abambo?
- Kodi anthu mu dera amaganiza mosiyana zokhudza kuchuluka kwa ana munthu okhala ndi HIV angakhale nawo?

3) Kodi anthu mu dera lanu amaganiza bwanji za kulera/ kutenga njira zopewera kukhala ndi mimba?

- Kodi amai ndi abambo amamva mosiyana zokhudza kugwiritsa ntchito kulera? Kodi anthu mu dera lanu amagwirizanao nazo zakugwiritsa ntchito kulera? Kodi anthu mu dera lanu samagwirizanao nazo zakugwiritsa ntchito kulera? Kodi anthu amenewa ndani? Kodi ngosiyana bwanji?
- Kodi wina angamve mosiyana zokhudza kugwiritsa ntchito maleredwe atakhala ndi HIV? (prompt – Kodi maganizo anu asintha kuchokera pamene munapezeka ndi HIV)
- Kodi ndi njira ziti zakulera inu mwamvako zoti amai kapena abambo akugwiritsa ntchito? Ndi njira iyi ikukhalako ngati ikugwira bwino? Kodi njira

- zina nzabwino kwambiri kwa amene ali ndi HIV kapena kwa iwo amene akumwa ma ARV?
- 4) Kodi amai ndi abambo amaphunzira bwanji za zokhudza kulera/ kupewa kutenga mimba?(Prompts – school,amai, agogo aakazi ,anzawo, madotolo kapena ena a zaumoyo, kumsika, atakhala ndi mwana,,sadziwa?)
- Kodi anthu okhala mu madera amasinthika atalandira uthenga atapezeka ndi HIV ?
  - Kodi uthenga okhudza kulera kapena kupewakutenga mimba umasinthira kwa iwo opezeka ndi HIV?
  - Nanga ngati akulandira ma ARV?
- 5) Mwa zonse, ndi ziti zimasuntha maganizo a abambo kapena amai kugwiritsa ntchito maleredwe/ kupewa kutenga mimba? (prompt – mtengo, kufikirika mosabvuta kwa ku kiliniki, maganizo a mai kapena akunyumba kapena okonedwa , kuchuluka kwa mimba, kuchuluka kwa ana amoyo, mabvuto a za chuma ?)
- Kodi amai/abambo ali ndi mantha kapena nkhwawa zokhudza kugwiritsa ntchito maleredwe? (prompt – zokhalapo zoipa za mankhwala mwakhalapo nazo kapena kumva kwa amai ena, kusabereka mutsogolo muno, zimene munamvapo kapena kuzionapo mwa inu kapena amai ena zomwe ndi mabvuto ndi njira za kulera?).
  - Kodi nkhwawazi nzosiyana ndi amwe ali ndi HIV?
  - Kodi izi zimasinthira kwa anthu amene akumwa ma ARV?.
- 6) Ngati panali njira yabwino kwambiri ya kulera kwa inu, zikhale za mtundu wanji otani? Prompt: opanda ma homoni,okhalitsa munthupi,otchipa.
- Mwamvako maganizo otani pa jekisoni? Lupu? Mapilitsi?
  - Kodi munamvako kuti wina wagwiritsako ntchito njira yanji ya ngozi yakulera? Chinachitika ndi chiani ndipo zotsatira zake zinatha bwanji? Analandilira kuti?
- 7)Ndifuna tiganize zokhudza njira zimene ziripo mu kapena mozungulira dera lino kwa munthu kufikira maleredwe. Ndi kuti kumene amai angalandire njira za kulera ndi mmemezingalipidwire.
- Ndi mitundu iti ikupezeka kumeneko?
  - Ndi mitundu ingati ya njira iliko kumeneko?( Mukuganiza kuti ndi njira zabwino zimenezo?)
  - Ndi ziti zimene anthu amakonda kapena samakonda zokhudza mathandizo amenewa? Kodi pali njira zina mathandizo amenewa angathe kupititsidwa patsogolo?)
  - Ndi zosiyana bwanji kwa anthu amene ali ndi HIV kapena omwe akumwa ma ARV? Kodi palikukakamizidwa kwambiri kapena pang'ono kugwiritsa ntchito njira zimenezi?
  - Kodi a zachipatala amapereka kwa abambo ndi amai a kachiroambo masankho ofanana a za kulera?
- 8)Ndikufuna kuganiza kwambiri zokhudza mmene anthu mu dera lanu amaonera kukhala ndi ana. Choyamba, tiyeni tiganize zoti mtsikana wamng'ono akufuna

kugwiritsa ntchito njira ya kulera. Kodi anthu mu dera amamva bwanji zokhudza izi?

- Kodi anthu angaganize mosiyana akanakhala osakwatiwa?
- Kodi anthu akanamva mosiyana akanakhala ndi ana 4 , nanga ana 6, ana 8
- Anthu akanamva bwanji akanakhala ndi HIV?
- Anthu akanamva bwanji akanakhala kuti akumwa mwa ARV?
- Nanga ngati okonedwa wake ali ndi HIV?

KUPUMULA:

Takulandilandinso . tiyeni tipite pamene tinalekezera. Timakambirana chikhumbokhumbo chokhala ndi mimba ndi kugwiritsa ntchito kulera.Papona ndikufuna kusintha tikambirane zambiri makamaka zokhudza kugwiritsa ntchito ma kondomu.

9) Munthawi yogonana, mwazonse amaganiza ndani kuti mwina kondomu igwiritsidwe ntchito?(onse awiri, abambo, amai)

- Nthawi iti amai angakhale ndi ufulu kupangitsa abambo kuvala kondomu?
- Kodi ndi zovomerezeka bwanji kwa amai kunyamula kondomu ndi kufunsa okonedwa agwiritse ntchito kondomu?
- Ngati amai anali osakwatiwa, kodi anthu angamve mosiyana?
- Anthu angaganize bwanji ngati ali ndi HIV?

Zingakhale zosiyana ngati okonedwa ake ali ndi HIV?10)Ngati wina akugwiritsa ntchito ya kulera, monga Lupu, kodi zingapangitse chisankho chogwiritsa ntchito kondomu pamene akugonana?

11) Kodi muchitidwe ogonana ungasinthe bwanji kwa amene ali ndi HIV (kugwiritsa ntchito kondomu, kudziletsa?)

- Kodi izi zikusiyana bwanji kutengera kukhala HIV kwa okonedwa wawo? Kungakhale kusintha kwa mtundu wanji kwa iwo amene akumwa ma ARV?(kodi kumwa ma ARV kungachepetse kugwiritsa ntchito kondomu?)
- Kodi ndi ziti zokhudzika zokhudza uchembere zimene zingakhale zosiyana kwa munthu amene ali ndi HIV?
- Ndi zofunikira ziti zingakhale zosiyana kwa iwo amene akulandira ma ARV??

12) Pomaliza ndikufuna nditsegule zokambirana kuona zokhudzika zina kapena zinthu zina zofunikira ku uchembere zimene zingakhudzide kutengera kuti munthu ali ndi HIV kapena akugwiritsa ntchito ma ARV.

- Kodi kukhala ndi HIV kapena kumwa ma ARV kungakhudze bwanji chikhaliidwe chokhala ndi ana? Kodi ndi zosiyana kwa abambo kapena amai?Kodi HIV kapena kumwa ma ARV zingapangitse zina zokhudza uchembere wanu/ kusamba mwa palipatali, kusabereka, kusiya kusamba, kupweteka kuchinena, kansa, kusintha kwa chilakolako cha kugonana)
- Ndi njira ziti ziripo zothandiza kukonza zofunikazi zokhudza uchembere?
- Mumakonda kapena kusakonda chani pa mathanzo amenewa?

- Ndi njira ziti mathandizo amenewa angapititsidwe patsogolo?

Pomaliza:

Tikunka kumalecheleche a zokambirana zathu. Kodi pali wina angakhale ndi ndemanga ili yonse kuonjezera pa zimene takhala tikukambirana tisanamalize? Zikomo kwambiri nonse chifukwa cha kubwera . Timayamika kupereka kwa mfundo zanu ku polojeketi ya kafukufukuyu ndipo tiri ndi chikhulupiro zokomana nazo mwagawanazi zidzathandiza amai ndi a bambo mutsogolo pa zofunikira za uchembere..

### Appendix 3

**Table 3: Codebook**

#	Code	Code definition
1	VCT	Captures all discussion of Voluntary HIV Counseling and Testing *Individual VCT.
2	Couples' VCT	Captures all discussion of Couples' HIV Voluntary Counseling and Testing.
3	HIV stigma and discrimination	Captures all discussion of unequal treatment of people living with HIV, including judgment, bullying (verbal and physical abuse), social isolation, and oppression. Stigma as belief-based and discrimination as action-based.
4	HIV sexual transmission	Captures all discussion of horizontal (sexual) transmission of HIV.
5	HIV viral load	Captures all discussion of the amount of virus in blood (quantitative and qualitative descriptors) and immunity as well as the meanings ascribed to these indicators.
6	HIV status	Captures all discussion of status - being HIV-positive or being HIV-negative, including diagnosis and disclosure of status.
7	Gender norms / roles	Captures all discussion of social and behavioral norms which are culturally constructed around being "a man" or "a woman" at a given time and place.
8	Condoms	Captures all discussion of condoms, including dual protection from pregnancy and STIs. Include references to NOT using condoms.
9	Contraception	Captures all discussion of contraception (traditional and modern family planning methods), including dual protection from pregnancy and STIs. Include references to NOT using contraception.
10	MTCT & PMTCT	Captures all discussion of vertical (mother-to-child) transmission (MTCT) of HIV and prevention of mother-to-child transmission (PMTCT) *Excludes VCT.
11	ART / treatment	Captures all discussion of treatment as it relates to HIV (e.g., antiretrovirals) *Excludes PMTCT.
12	Pregnancy and antenatal care	Captures all discussion of beliefs about men's role in pregnancy and antenatal care.

## Appendix 4

### Emory University IRB Approval

<https://eresearch.emory.edu/Emory/Doc/0/1Q30LJGN7VO4L...>



EMORY  
UNIVERSITY

Institutional Review Board

TO: Lisa Haddad  
Principal Investigator  
FAMILY PLANNING

DATE: August 25, 2011

RE: **Expedited Approval**  
IRB00051780  
Exploring the Impact of HIV and ART on Knowledge, Attitudes and Practices in Reproductive Health in Lilongwe, Malawi

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory category F7 as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 8/25/2011 and granted approval effective from **8/25/2011** through **8/24/2012**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Consent Form: Focus groups was approved
- Consent Form: Quest was approved

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at [www.irb.emory.edu](http://www.irb.emory.edu), immediately, promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, study design, you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you

Andrea Goosen, MPH  
Research Protocol Analyst

*This letter has been digitally signed*

CC:

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Emory University  
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322  
Tel: 404.712.0720 - Fax: 404.727.1358 - E mail: [irb@emory.edu](mailto:irb@emory.edu) - Web: <http://www.irb.emory.edu/>  
*An equal opportunity, affirmative action university*

## National Health Sciences Research Committee, Malawi Ministry of Health Approval

Telephone: + 265 789 400  
Facsimile: + 265 789 431  
e-mail doccentre@malawi.net  
All Communications should be addressed to:  
The Secretary for Health and Population



*In reply please quote No. MED/4/36c*

MINISTRY OF HEALTH  
P.O. BOX 30377  
LILONGWE 3  
MALAWI

26<sup>th</sup> January 2012

Sam Phiri  
UNC Project

Dear Sir/Madam,  
**Re: Protocol # 935: Exploring the impact of HIV and ART on knowledge, attitudes and practices in reproductive health in Lilongwe, Malawi**

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to conduct the above titled study.

- **APPROVAL NUMBER** : NHSRC # 935  
The above details should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL DATE** : 26/01/2012
- **EXPIRATION DATE** : This approval expires on 26/01/2013  
After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING** : All serious problems having to do with subject safety must be reported to the National Health Sciences Research Committee within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using standard forms obtainable from the NHSRC Secretariat is required before implementing any changes in the Protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on Telephone No. (01) 724418, 0999218630 or by e-mail on moh@gmail.com
- **Other**:  
Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database.

Kind regards from the NHSRC Secretariat.

.....  
**FOR CHAIRMAN, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE**

**PROMOTING THE ETHICAL CONDUCT OF RESEARCH**  
Executive Committee: *Dr.C.Mwansambo (Chairman), Prof. Mfutsu Bengo (Vice Chairperson)*  
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB  
(IRB Number IRB00003905 FWA00005976)